

2001 SEATTLE-KING COUNTY HIV/AIDS CARE SERVICES COMPREHENSIVE NEEDS ASSESSMENT



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I. Summary

A. Background

Between the months of November 2000 and August 2001, Public Health - Seattle & King County's HIV/AIDS Program and the HIV/AIDS Planning Council for the Seattle Eligible Metropolitan Area (EMA) conducted a comprehensive needs assessment of HIV/AIDS care services in King County. Quantitative epidemiological data, including current infection and case trends, had already been collected and analyzed by Public Health's HIV/AIDS Epidemiology Program and were used in this comprehensive process.

The 2001 Needs Assessment was a research and planning activity that sought to:

- identify the extent and types of existing and potential care service needs among persons living with HIV/AIDS in King County
- examine the current service delivery system in the County, particularly the system's ability to ensure that persons living with HIV/AIDS can effectively obtain and maintain access to primary medical care
- determine the extent of unmet needs or underutilized resources in order to plan appropriate care services
- analyze and compare two-year trends in service utilization, priorities, gaps and access barriers

The main objective of the 2001 Needs Assessment process was to provide data to inform decisions related to the Planning Council's prioritization of care services for the Ryan White CARE Act's Title I funding allocation process. (See Appendix A for a list of Planning Council- approved Ryan White service categories.) Additional goals of the project were to:

- assess the current Continuum of Care in Seattle-King County, with the goal of strengthening the system and working towards greater collaboration among diverse communities and service systems;
- provide legislatively mandated information to the federal Health Resources Services Administration (HRSA) on service needs and system response, and
- provide planning information for agencies, organizations, and health care providers

Efforts were made to collect information from as wide a spectrum of persons living with HIV/ AIDS in King County as possible, ranging from individuals who were are HIV positive but not yet symptomatic to persons with end-stage illness. Traditionally under-served populations were given particular focus, including persons who were homeless, those who were dually or triply diagnosed (with HIV, mental illness and/or chemical dependency), women, youth/young adults, persons of color, and persons living in South and East King County.

This HIV/AIDS Needs Assessment provides a “snapshot” of community services, priorities, gaps and access barriers as identified by consumers and providers in 2001. By nature, needs assessment processes must be ongoing to reflect the changing nature of the service delivery system, treatment advances, funding availability, and epidemic trends. Public Health - Seattle & King County, in conjunction with the Planning Council, is currently planning future needs assessment projects that will augment the findings of this most recent process.

B. Methods

Several strategies were employed to solicit input in the needs assessment process:

- creation and distribution of written surveys to persons living with HIV/AIDS (PLWH) throughout King County (538 valid surveys returned)
- creation and distribution of written surveys to providers of HIV-related services throughout King County, including medical, dental, mental health, substance use treatment, and support services (256 valid surveys returned)
- key informant interviews with 28 service providers
- focus groups conducted with 11 sub-populations of PLWH

Public Health - Seattle & King County (Public Health) has conducted several other needs assessment processes related to HIV/AIDS care services during the past two years. These include:

- The 2000 “Not in Care” Interview Project, a focused assessment process conducted by the Planning Council and Public Health that attempted to interview PLWH who, for whatever reasons, were not accessing primary outpatient medical care for their HIV infection. (See Appendix B for summary data from the “Not in Care” Project.)
- The 2000 HIV/AIDS Care/Prevention Collaboration Project, that explored whether HIV prevention providers in Seattle-King County appropriately refer their HIV+ clients into care services and whether HIV care service providers discuss sex and drug use risk reduction with clients and make appropriate referrals for clients with ongoing risk reduction needs. (See Appendix C for a summary article on the project, reprinted from the Washington State/Seattle - King County HIV/AIDS Epidemiology Report, 1st Half 2000.)
- The 1999 Comprehensive Needs Assessment, which employed similar data-gathering strategies as the current process to identify consumer- and provider-identified service utilization rates, service priorities, gaps in services, and barriers to accessing services.

C. General Findings from the 2001 Needs Assessment

As in previous assessments, most service providers report that their caseloads are comprised primarily of gay, white men. This is particularly true for general medical providers and staff at AIDS service organizations. However, trends that first emerged in 1997 continue. Providers from across the Continuum of Care report increases in the number of clients seen who are women (from 13% in 1999 to 18% in 2001), persons of color (from 27% in 1999 to 29% in 2001), heterosexual injection drug users (from 11% in 1999 to 15% in 2001) and clients who live outside of Seattle (from 19% in 1999 to 23% in 2001). Providers also noted increases in the numbers of clients who are dually and/or triply diagnosed (with HIV, mental illness and/or chemical dependency).

Providers report that the majority of their clients have good access to medications and are responding well to the treatments. However, providers increasingly report that they are seeing more clients who are not responding as well to their HIV medications as they did several years ago. This translates into increasing numbers of clients who are developing opportunistic infections and requiring intensive medical care. Providers also noted an increase in AIDS-related mortality, reversing a trend in significantly decreased mortality that had begun in the mid-1990's.

Providers also reported ongoing increases in the numbers of clients who are presenting with mental illness. Each of the 28 providers interviewed as part of the key informant interview process noted that depression is on the rise among their caseloads. The overall percentage of clients that providers reported as presenting with mental illness rose from 32% in 1999 to 47% in 2001. Providers also reported that more clients with severe mental illness continue to enter the care service system, including increasing numbers of clients with personality disorders and psychoses. Providers note that serving these clients is very time and labor intensive, requiring greater coordination than ever between the HIV and mental health systems.

Providers also noted that they are seeing an increase in the number of clients for whom English is not their primary language. In 1999, providers reported that an average of 3% of their caseloads were primarily Spanish speaking. By 2001, that figure had risen to 5%. Providers also reported seeing increasing numbers of West African refugee PLWH, particularly clients from Ethiopia and Eritrea.

In general, consumer focus group participants expressed satisfaction with the quality of most of the services offered in the King County Continuum of Care. In particular, consumers noted that medical care was available to them and their peers when they chose to access it and that the quality of care they received was excellent. The very small number of consumers who were not currently using medical care or taking HAART medications stated that this was by personal choice, not due to lack of access to care.

Concerns about case management arose more frequently in the 2001 assessment process than in any of the previous needs assessments. Two issues were highlighted:

- **Lack of case managers of color:** Consumers of color often expressed concerns about what they viewed as a lack of culturally sensitive case management services. Although most of the focus group participants felt that their case managers were doing an adequate job in assisting them, concerns were raised regarding case managers' abilities to comprehend and respond effectively to the cultural norms of non-white consumer populations. As several consumers and key information providers noted, it is becoming increasingly important for case managers to be bicultural, not merely bilingual.

- Lack of service continuity: Consumers from across the spectrum of sub-populations were frustrated by the frequency of staff turnover in case management agencies. Focus group participants, particularly men who have sex with men (MSM) and residents of South and East King County, noted that it was very difficult to maintain trust and develop working relationships when the person assigned as their case manager kept changing. Some consumers reported having had four or five case managers since 1995, due to staff attrition.

Consumers also expressed dissatisfaction with what they perceive to be decreasing availability of volunteer-driven services. These include home chore services, transportation, food and meal delivery and one-on-one peer support. This concern was voiced most frequently by consumers of color and non-Seattle residents. Consumers noted that it was often difficult to recruit and maintain volunteers from their communities and that this has had a negative impact on their access to these services.

D. Service Utilization

Utilization rates were highest among survey respondents in the areas of primary medical care, client advocacy programs, case management, and dental care. Use of services among survey respondents has remained relatively constant in most categories during the past few years, although several significant changes have emerged since 1999. Use of case management services has risen significantly, increasing from 72% of respondents in 1999 to 79% in 2001. Significant increases were also seen in use of insurance programs (up from 50% in 1999 to 57% in 2001) and mental health therapy and counseling (up from 43% to 49%). No significant utilization decreases were noted in any service category during the past two years.

Several differences emerged regarding utilization patterns reported by sub-populations of PLWH on the consumer survey. Although few differences emerged related to gender, male PLWH were significantly more likely than females to use case management services (81% versus 67%), while females were more likely to use substance use treatment and counseling (25% versus 15%). Reported service utilization by PLWH who are injection drug users (IDU) was greater than non-IDU in several categories, most notably case management (87% of IDU versus 77% of other consumers), housing assistance (62% versus 42%) and food and meal programs (60% versus 46%).

Greater differences emerged in the utilization of most services based on race than in past assessments. In general, African-American PLWH reported higher utilization rates than white PLWH. These differences were most significant in the areas of transportation services (50% versus 29%), peer emotional support counseling (66% versus 55%), emergency financial assistance (48% versus 38%) and housing assistance (61% versus 50%). Conversely, utilization rates among white and Latino/a PLWH were relatively similar. Due to the small number of American Indian and Asian/Pacific Islander survey respondents, it is not possible to make similar statistical comparisons.

In previous years, a significantly lower percentage of East and South King County consumers reported currently accessing outpatient medical care and other clinical services in comparison to Seattle residents. Although non-Seattle residents reported higher rates of medical care utilization than in prior years, the percentage remains lower than for Seattle consumers (91% versus 96%). Utilization rates for other services are relatively similar, with the exception of insurance programs (used by a greater proportion of non-Seattle residents: 64% versus 55%) and mental health therapy and substance use counseling (used by greater percentages of Seattle PLWH: 51% versus 39% and 19% versus 5%, respectively).

As noted in previous assessment reports, homeless PLWH exhibit utilization rates which are similar in most respects to other consumers once they enter the care system. Providers noted that their homeless clients use a wide variety of available services, with increased utilization of case management, mental health and chemical dependency treatment than in previous years.

E. Service Priorities

Consumers ranked primary medical care as the highest service priority, followed by dental care, case management, housing assistance and housing related services and insurance programs. Relative priority rankings changed little between 1999 and 2001 for most services. Drug prescription programs, ranked as the top consumer priority in 1999, dropped to the sixth highest priority (ranked as a priority by 62% of consumers in 1999 and 40% in 2001). Conversely, consumers were more likely in 2001 to prioritize insurance programs, which moved up from eighth to fifth in the priority rankings (34% in 1999 and 41% in 2001). Food and meal programs dropped from the sixth highest priority in 1999 (35% listing the service as a priority) to a tie for tenth in 2001 (29%).

In addition to the aforementioned services, three other categories experienced significant changes in the overall percentage of consumers who listed them as priorities between the two survey years. These included ambulatory medical care, legal assistance and mental health therapy/counseling. Sixty-three percent of respondents prioritized ambulatory care in 2001, up from 55% in 1999. The percent of consumers who prioritized mental health therapy also increased, from 23% in 1999 to 29% in 2001. Legal assistance was significantly less likely to be listed as a priority, dropping from 21% of respondents in 1999 to 16% in 2001.

Providers ranked ambulatory care as the highest service priority for their clients, followed by case management, mental health therapy/counseling, drug prescription programs, and substance use treatment/counseling. Similar to previous years, providers were significantly more likely than consumers to prioritize substance use treatment (49% versus 9%) and mental health counseling (63% versus 29%). This discrepancy was noted by providers during the key informant interview process, many of whom reported increases in the incidence of dual and triple diagnoses (HIV/mental illness/chemical dependency) among their client populations, coupled with consumer resistance to and/or lack of access to these services.

MSM survey respondents were statistically more likely than other consumers to prioritize clinical services, such as primary medical care (67% of MSM versus 49% of non-MSM), dental care (59% versus 45%) and mental health therapy and counseling (31% versus 18%). Conversely, MSM were less likely than other consumers to prioritize support services such as emergency financial assistance (28% versus 39%), food and meal programs (25% versus 36%), housing assistance (44% versus 60%) and client advocacy (33% versus 43%).

Continuing a trend first observed in 1995 and continuing in recent years, persons of color were significantly more likely than whites to prioritize housing assistance (55% versus 40%). Providers noted that many of their clients of color were living in low income housing prior to their AIDS diagnoses, often with family members who are no longer able to care for their medical needs. For immigrant or refugee PLWH, such as the emerging number of non-resident Latino/a PLWH and PLWH from West African, the need for housing is also crucial.

Consumers of color were also significantly more likely than whites to prioritize client advocacy services (45% versus 29%). PLWH of color who attended focus groups noted that verbal and written information about HIV disease and medications is difficult to obtain within their communities. Consumers of color stressed the importance of peer advocacy programs, from which they could learn about access to the system from persons who understand their language and cultural norms.

Female and male PLWH reported more similarities than differences in service prioritization. Nevertheless, several services were more highly prioritized by women than men, including housing services (60% versus 45%), client advocacy (particularly peer advocacy) (50% versus 33%) and peer emotional support (40% versus 26%). Women were significantly less likely than men to prioritize clinical services, such as primary medical care (45% versus 67%), dental care (39% versus 58%) and drug prescription programs (29% versus 41%).

Geography did not appear to play a major factor in the ways in which consumers prioritized most services. However, East County PLWH were more likely than Seattle and South King County consumers to prioritize telephone referral programs (29% versus 8% and 9%, respectively) and less likely than other consumers to prioritize primary medical care (46% versus 64% of Seattle PLWH and 63% of South County PLWH).

F. Service Gaps

Consumers identified lack of access to emergency financial assistance as the number one service gap (services which consumers stated they needed, but could not get). Almost one quarter of survey respondents identified this gap. Among the sub-components of this service category, 19% of respondents identified a gap in help paying utility bills and 16% identified a gap in help paying for groceries.

The only other service that was ranked as a gap by more than a 20% of survey respondents was housing assistance and housing related services. Of the component services in this category, 14% of consumers identified a gap in rental assistance and 13% reported that they needed but could not get help in finding housing.

Other services that ranked among the top five service gaps for consumers were client advocacy programs, peer emotional support, and food and meal programs. Within the client advocacy category, the largest gaps were reported in the non-case management financial benefits counseling (identified as a gap by 11% of consumers) and peer advocacy (10%). In the emotional support category, the largest gaps were identified in one-on-one peer support (14%) and support groups (12%).

As in previous years, outpatient medical care continued to be identified as a gap by a very small number of consumers. Only 1% of survey respondents (6 out of 538) stated that they needed but could not access outpatient medical care. Five percent of consumers reported that they needed but could not access Washington State's AIDS drug assistance program.

The top five services which providers identified as lacking for their clients were housing assistance and housing related services, substance use treatment and counseling, mental health therapy and counseling, client advocacy and dental care. Providers also noted that outpatient medical care was not a large gap for the clients, with only 2% of providers identifying a gap in provision of this service.

MSM were fairly consistent with other populations in ranking service gaps. However, significantly lower percentages of MSM identified gaps in access to emergency financial assistance (22% versus 34%), food and meal programs (8% versus 18%), and case management (3% versus 9%). In general, MSM of color were more likely than white MSM to report gaps in the provision of services. MSM of color were almost twice as likely as white MSM to identify gaps in housing services (29% versus 15%). Other key differences emerged in the areas of peer counseling (27% versus 17%), legal assistance (18% versus 8%), and adult day health (15% versus 2%). Within the category of peer counseling, the largest gap emerged in one-on-one peer support (24% versus 11%), with particularly large gaps noted by Latino MSM.

Continuing a trend first reported in 1999, IDU survey respondents were less likely than other consumers to report unmet service needs. The only service that was statistically more likely to be identified as a gap by IDU than by non-IDU PLWH was substance use treatment (12% versus 3%). As noted by providers, once they enter substance use treatment or counseling, IDU PLWH seem to exhibit utilization rates of HIV-related services that are very similar to other consumers. However, a significant number of HIV+ IDU are not currently receiving care for their substance use and may forego using HIV-related services until they feel ready to address their chemical dependency issues.

Persons of color were significantly more likely than white PLWH to identify gaps in almost one third of all service categories. The greatest disparities in access emerged in the areas of adult day health programs (15% versus 2%), housing assistance (27% versus 16%), telephone referrals to care (17% versus 6%) and peer support counseling (27% versus 17%).

In comparison to previous surveys, differences in service access based on gender were reported in very few service categories. However, 32% of female respondents noted difficulty in accessing emergency financial assistance, as compared to 22% of males. Women were also more likely than men to identify gaps in housing assistance (25% versus 18%) and in food and meal programs (21% versus 8%).

Very few differences in access to services emerged related to geography (East and South King County PLWH versus Seattle PLWH) or homeless status. As expected, homeless consumers were far more likely than non-homeless persons to report gaps in housing assistance and related services, particularly help in finding low income housing.

G. Access Barriers

Similar to previous assessments, the two main barriers identified by consumers in accessing services were lack of information about available services and inability to afford services. The percentage of consumers who identified being unable to access services due to disability-related eligibility criteria, lack of comfort in agency settings, and lack of geographic access to services decreased significantly from 1995 to 1999, and remains low in 2001.

The identification of access barriers was remarkably similar across the spectrum of PLWH sub-populations surveyed. However, focus group participants and service providers noted that cultural and economic factors continue to inhibit certain clients from accessing the services they need. These include language barriers for clients with limited or no English language proficiency, cultural norms about seeking medical care and taking medications, chaotic lifestyles, and unstable living situations.

Providers also noted that co-morbidities can severely hinder their clients' abilities to access needed services. These include mental illness, active substance use and histories of incarceration. Unfortunately, providers also noted that the percentage of clients on their

caseloads who are dually or triply diagnosed has increased, leading to greater difficulties for increasing numbers of clients in obtaining services and increased provider time and energy required to assist these clients.

H. Access Services

In response to the Health Resources and Service Administration's increased focus on medical care access and engagement, the Planning Council added a new component to the 2001 consumer and provider surveys. The 2001 survey asked consumers and providers to identify the services they felt were most important in helping them or their clients access or maintain medical care ("access services").

In general, consumer rankings of access services were extremely similar to their rankings of service priorities. Consumers identified case management as the most important service in helping them get or maintain medical care, followed by insurance programs, dental care, client advocacy, Washington State's AIDS drug assistance program and housing assistance.

Providers were in agreement with consumers regarding the importance of case management in helping PLWH access medical care, also ranking it as the highest access services. Providers also ranked client advocacy and prescription drug programs among their top five access services. However, consistent with divergent provider/consumer opinion about the importance of mental health and substance use counseling, providers ranked these services as the third and fourth highest priorities, while consumers ranked them 8th and 19th, respectively.

II. Epidemiological Profile of HIV/AIDS in Seattle-King County

NOTE: Parts of this section have been excerpted from HIV/AIDS Epidemiology Profile for Community Planning, June 2001, the Monthly HIV/AIDS Epidemiology Report (published by Public Health – Seattle & King County’s HIV/AIDS Epidemiology Unit) and the HIV/AIDS Epidemiology Report - 2nd Half, 2000 (published jointly by Public Health and the Washington State Department of Health). For more in-depth information about the epidemiology of HIV/AIDS in King County and Washington State, please refer to these and other publications produced by the aforementioned programs. Information can also be obtained on the Public Health website at www.metrokc.gov/health/apu.

A. Summary

HIV infection and AIDS continue to have a major impact on the health of King County residents. As of 10/31/01, 6,341 cumulative AIDS cases had been reported in King County. Of these, 3,650 (58%) have died. Between 6,000 and 9,000 residents of the county are currently estimated to be infected with HIV.

Fortunately, AIDS-related mortality has declined sharply in recent years due to a decreasing annual incidence of AIDS and the efficacy of new drug treatment regimens. In 1994, HIV/AIDS deaths ranked second behind cancer in the highest number of potential years of life lost before age 65 in King County. In 2001, that number dropped to the sixth highest.

The geographic distribution of AIDS in King County varies widely. The highest overall average annual AIDS rate is in Seattle (22.3 per 100,000 population). Within Seattle, rates range from a high of 99.1 in the Central Area to a low of 8.7 in North Seattle. It is important to note that there continues to be a significant decline in the overall average annual rate of AIDS in Seattle since the 1993-1995 epidemiology report, in which the average annual rate was 70.8 per 100,000 population.

The overall average rate for King County outside Seattle has also declined to 4.3 per 100,000 population. Rates range from a high of 8.7 in Bellevue to 1.2 in Southeast King County.

Gay and bisexual men continue to be the population most heavily affected by HIV infection and AIDS. Young gay men in their late teens and early twenties are at particularly high risk of infection. In King County, 79% of cumulative AIDS cases have been men who have sex with men (MSM), with an additional 11% among MSM who also inject drugs. While the proportion of AIDS cases that are gay or bisexual men has decreased gradually over time, the proportion of cases in women and people of color have increased.

African-American, Hispanic and American Indian/Alaska Native residents of King County are disproportionately affected by HIV/AIDS. People of color represented 11% of reported AIDS cases from 1982-1986; this figure has risen to 35% of reported cases in 1998-2000. Between 1997 and 1999, the average annual rate of AIDS in African-Americans, Hispanics and American

Indians/Alaska Natives was 36.0, 35.9 and 33.0 per 100,000 respectively, compared to 10.0 per 100,000 in whites and 3.4 per 100,000 in Asian/Pacific Islanders. Among women, this discrepancy was even greater: the rate of AIDS per 100,000 in African-American women was 17.3 and in American Indian/Alaska Native women was 7.2, versus 0.9 in White women.

B. Description of King County

Geography: King County is 2,128 square miles in size. While the county has only 3% of the state's land area, it is home to 29% of the state's population. King County ranks as the twelfth most populous county in the United States.

Seattle and the suburban cities: Eight of the 20 largest cities in Washington are in King County. Seattle (2000 population: 563,374) is the largest city within King County (2000 population: 1,737,034). The county contains 39 incorporated cities, which account for approximately 79% of King County's population. Thirty-two percent of county residents reside in Seattle, 47% in incorporated suburban cities, and 21% in unincorporated King County.

Racial composition: The overall racial composition of King County in 2000 was 76% white, 11% Asian/Pacific Islander, 6% Hispanic or Latino, 5% African-American, and 1% American Indian/Alaska Native. Between 1990 and 2000, more than half of the new residents in Seattle were Asians or Hispanics. The region's minority population is far more spread out in the suburbs than in the past. Bellevue has the largest proportion of Asians (17%) of any city in King County. The cities of Renton and SeaTac now have about the same percentage of blacks as Seattle.

Socioeconomic status: The median household income in King County is \$49,000. Approximately nine percent of families are living below Federal Poverty Level, with persons of color being almost three times as likely as whites to be living in poverty. The poverty rate was somewhat higher in the city of Seattle, at 12%. Within the county, areas with the largest percentage of the population below poverty level were Central Seattle, Southeast Seattle, Auburn, and Southeast King County.

C. HIV/AIDS in King County: Distribution and Trends

The Seattle metropolitan statistical area (King, Snohomish and Island counties) ranked 56th in AIDS case rates among the 101 metropolitan areas in the United States with populations of 500,000 or more for cases reported between 7/99-6/00. In 1995, the Seattle area ranked 35th among these metropolitan areas. The rate of reported AIDS cases in the Seattle metropolitan area was 11.4 per 100,000 population for the period of 7/99-6/00, down from a rate of 26.1 in 1996.

King County has the highest rate of AIDS of all Washington State counties. Although King County has less than one-third of the state's population, two-thirds of the state's AIDS cases have been diagnosed and reported in King County residents. Since the mid-1980's, however, there has been a steady trend toward proportionately fewer AIDS cases occurring in King County. Only 52% of Washington State's AIDS cases occurred in King County in 1999, compared to 64% in 1993-94 and 75% in 1986-87.

AIDS cases and trends by gender: Of the total 6,096 AIDS cases diagnosed in King County through 2000, 5,803 (95%) were male and 293 were female (5%) (Table 1). Females as a percent of annual AIDS cases have risen over time in King County, from 2-3% in 1987-90 to 14% in 2000.

AIDS cases and trends by race/ethnicity: The majority of AIDS cases in King County have occurred among whites. However, in the past decade, people of color have been increasingly affected by AIDS, accounting for 39% of the reported cases in 1999, compared to 19% in 1992-94. African-Americans and Hispanics also account for a disproportionate number of cases relative to their population in the county.

AIDS cases were diagnosed among African-Americans for the three-year period 1997-1999 at the average annual rate of 36.0 per 100,000, 35.9 per 100,000 among Hispanics, and 33.0 among American Indian/Alaska Natives. Comparable rates are 10.0 for whites and 3.4 for Asians/Pacific Islanders.

AIDS cases and trends by age: AIDS affects persons of a relatively young age. Almost half (48%) of all reported cumulative King County AIDS have been between 30 and 39 years old at the time of their diagnosis, 25% were 40-49 years old, and 17% were 20-29 years. A higher proportion of female (29%) than male (17%) cases was under 30 at the time of their diagnosis.

Pediatric AIDS and HIV disease in King County: A very low proportion of AIDS reports have been pediatric cases (defined as under 13 years of age at the time of AIDS diagnosis). As of the end of 2000, a cumulative total of 15 pediatric AIDS cases had been diagnosed and reported, accounting for 0.2% of cumulative King County AIDS cases. In comparison, the United States figure is 1.3%.

AIDS cases by mode of exposure: Among the cumulative adult/adolescent (13 years and older) male AIDS cases, 75% have been men who had sex with men (MSM), 10% are MSM who also injected drugs (IDU), 6% were heterosexual IDU, and 3% were associated with heterosexual transmission (Table 1). The route of transmission among King County adult/adolescent males remained relatively stable between 1987 and 1994. In 1995 through 1997, however, a higher proportion of cases (8%) were associated with IDU and a lower proportion with male-male sex (68%) compared to previous years. In 1999, the proportion of male cases attributed to same-sex sexual activity was 69%, with 11% attributed to MSM/IDU. Among the 293 King County adult/adolescent female AIDS cases, 138 (47%) were attributed to heterosexual contact and 76 (30%) were related to injection drug use, compared to 40% and 27% of all United States adult female AIDS cases, respectively.

Table 1. AIDS Trends in King County: Cases Diagnosed through 2000

Category	Cases Diagnosed In 1996		Cases Diagnosed In 1997		Cases Diagnosed in 1998		Cases Diagnosed in 1999		Cases Diagnosed in 2000 ¹		Cumulative Cases Reported 1982-2000 ²	
TOTAL CASES	418		295		250		180		113		6,096	
SEX	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Male	388	(93)	271	(92)	227	(91)	163	(91)	97	(86)	5,803	(95)
Female	30	(7)	24	(8)	23	(9)	17	(9)	16	(14)	293	(5)
RACE/ETHNICITY												
White, not Hispanic	307	(73)	202	(68)	162	(65)	124	(69)	69	(61)	4,882	(80)
Black, not Hispanic	53	(13)	41	(14)	46	(18)	27	(15)	26	(23)	632	(10)
Hispanic	36	(9)	31	(11)	30	(12)	21	(12)	16	(14)	374	(6)
Asian/Pacific Islander	10	(2)	9	(3)	6	(2)	3	(2)	1	(1)	117	(2)
Am. Indian/AK Native	12	(3)	12	(4)	6	(2)	5	(3)	1	(1)	91	(1)
AGE AT DIAGNOSIS (YRS)												
< 13	3	(1)	1	(<1)	0	(0)	0	(0)	1	(1)	15	(<1)
13-19	1	(<1)	1	(<1)	0	(0)	1	(<1)	0	(0)	12	(<1)
20-29	59	(14)	46	(16)	32	(13)	27	(15)	21	(19)	1,041	(17)
30-39	211	(50)	143	(48)	122	(49)	81	(45)	44	(39)	2,955	(48)
40-49	116	(28)	72	(24)	63	(25)	56	(31)	34	(30)	1,532	(25)
> 49	28	(7)	32	(11)	33	(13)	15	(8)	13	(12)	541	(9)
EXPOSURE CATEGORY³												
Male/male sex	286	(68)	186	(63)	159	(64)	117	(65)	64	(57)	4,600	(75)
Injection drug use (IDU)	35	(8)	15	(5)	24	(10)	16	(9)	15	(13)	346	(6)
IDU & male/male sex	32	(8)	34	(12)	23	(9)	16	(9)	12	(11)	623	(10)
Heterosexual contact	23	(6)	16	(5)	11	(4)	7	(4)	7	(6)	194	(3)
Hemophilia	3	(1)	3	(1)	0	(0)	1	(1)	0	(0)	30	(1)
Transfusion	0	(0)	3	(1)	3	(1)	1	(1)	0	(0)	53	(1)
Parent at risk/has HIV	3	(1)	1	(<1)	0	(0)	0	(0)	1	(1)	14	(<1)
Undetermined/other	36	(9)	37	(13)	30	(12)	22	(12)	14	(12)	236	(4)
¹ Provisional data due to reporting delays ² Cumulative cases in King County residents meeting the 1993 CDC surveillance case definition of AIDS diagnosed and reported as of 12/31/00; includes cases diagnosed prior to 1993 ³ Cases with more than one risk factor other than the combinations given are tabulated only in the category listed first												

Comparison of AIDS in Seattle and the rest of King County: Among the 6,096 cumulative AIDS cases diagnosed through 2000, 82% resided in the city of Seattle and 18% lived in other areas of the county. Compared to Seattle residents reported with AIDS, those living outside Seattle were more likely to be female (10% versus 4%), and to have been exposed through injection drug use (8% versus 5%) or heterosexual contact (7% versus 2%).

Estimated number of people with HIV in King County: Between 6,000 and 9,000 King County residents are estimated to be infected with HIV, including more than 2,500 persons living with AIDS (Table 2).

Table 2. HIV+ Estimates of Selected Populations in King County, 2000

CATEGORY	MIDPOINT		RANGE
	Number	Percent	Number
GENDER			
Male	6,825	91%	5,460 – 8,190
Female	675	9%	540 – 810
AGE GROUP			
<13 years	45	<1%	35 – 55
13 – 19 years	95	1%	75 – 110
20 – 29	1,725	23%	1,380 – 2,070
30 – 39	3,525	47%	2,820 – 4,230
40 – 49	1,650	22%	1,320 – 1,980
50 and over	450	6%	360 – 540
HIV EXPOSURE			
Male/male sex	5,250	70%	4,200 – 6,300
MSM/IDU	750	10%	600 – 900
IDU Heterosexual	525	7%	400 – 650
Heterosexual	375	5%	300 – 450
Pediatric exposure	45	1%	45 – 55
Other/unknown	525	7%	420 – 630
RACE/ETHNICITY			
White	5,500	74%	4,440 – 6,660
Black	1,050	14%	840 – 1,260
Hispanic	600	8%	480 – 720
Asian/Pacific Islander	150	2%	120 – 180
American Indian/AK Native	200	2%	120 – 180
KING COUNTY TOTAL	7,500		6,000 – 9,000

HIV/AIDS-related mortality: As of 10/31/01, 6,341 cumulative AIDS cases had been reported in King County. Of these, 3,650 (58%) have died. From 1995 through 1999, the number of AIDS-related deaths in King County declined dramatically. This decline averaged 50% per year between 1995-97. Deaths due to AIDS peaked in King County in 1995 at 439, but fell to 280 in 1996, 102 in 1997 and 88 in 1998. In 1999, only 51 deaths were reported. However, preliminary data from 2000 suggest that there may have been a slight increase in AIDS deaths during the year. The net result of the changes in deaths and AIDS incidence is that the number of persons living with AIDS continues to increase. As of 3/01, 2,600 King County residents were living with AIDS as compared to about 1,750 in 1995.

Persons living with HIV/AIDS: HIV case reporting in Washington State was implemented on September 1, 1999. In the eighteen months between 9/1/99 and 3/1/01, a total of 310 newly diagnosed HIV (non-AIDS cases) were reported in King County residents. HIV (non-AIDS) case reports have also been received for 1,594 persons currently receiving health care who were diagnosed with HIV prior to the implementation of HIV reporting on 9/1/99. These include King County residents reported as having progressed to AIDS and not known to have died. In addition, 2,600 persons living with AIDS had been reported and are not known to have died, resulting in a current total of 4,118 King County residents living HIV/AIDS reported to Public Health.

The epidemiologic profile of the recent HIV cases is likely to better characterize recent HIV transmission patterns compared to AIDS cases or persons infected less recently and currently living with HIV/AIDS. Compared to persons currently living with HIV/AIDS, the 310 King County residents with recently-diagnosed HIV infection are more likely to be:

- Female (16% versus 9%)
- African-American (19% versus 14%)
- Hispanic (12% versus 8%)
- Currently less than 30 years of age (26% versus 7%)

By HIV exposure category, a larger number and proportion of female cases are attributable to heterosexual contact compared to males (38% versus 1%), as well as injection drug use (27% versus 5%). Females living with HIV/AIDS also tend to be younger (17% are ages 13-29 as compared to 5% of males) and more likely to be African-American (39% versus 11%) or Native American (5% versus 1%). The proportion of Hispanics and Asian/Pacific Islanders living with HIV are similar for males and females.

III. Methods

The needs assessment process used several strategies to gather input. The centerpiece of the process was the creation and distribution of written surveys to persons living with HIV/AIDS (PLWH) throughout King County. Other components of the needs assessment process included a written service provider survey, focus groups of targeted consumer sub-populations and key informant interviews with service providers.

A. Consumer Surveys

The 2001 consumer survey targeted persons living with HIV/AIDS throughout King County. The survey was based on ones developed in previous needs assessment processes. (See Appendix D for a copy of the consumer survey instrument.) The HIV/AIDS Planning Council's Needs Assessment Work Group oversaw the development of the survey instrument, and staff from Public Health – Seattle & King County were responsible for survey distribution, collection and analysis.

The Planning Council sought to collect information on a wide spectrum of persons living with HIV/AIDS in King County, ranging from individuals who were HIV positive but not yet symptomatic to persons with end-stage illness. The process emphasized traditionally underserved populations, including persons who were homeless, were dually or triply diagnosed (with HIV and mental health or substance use histories), women, youth/young adults, persons of color and persons living in South and East King County. Survey forms were created both in English and Spanish language versions.

The survey inquired about 36 types of HIV/AIDS-related services offered in the King County Continuum of Care. Consumers identified each service either as one that they needed and used, did not need, or needed but could not get. For services that were identified as “need, but cannot get,” consumers were asked to identify the reason(s) why this service was unavailable. The survey also asked consumers to choose up to seven of the services that they would consider most important for them.

In response to an increased focus on medical care access by the Health Resources Services Administration (HRSA), the Planning Council added a new component to the 2001 survey. The survey asked consumers to identify the services they felt were most important in helping them access or maintain medical care (“access services”). The survey also collected demographic information, as well as information related to HIV health status and medication adherence issues.

In creating the survey instrument, the Planning Council made extensive efforts to safeguard the anonymity of survey respondents. Survey instructions explicitly stated that consumers should not include their names, addresses or phone numbers on return surveys. To further safeguard respondents' confidentiality, the surveys were pre-addressed to the “Planning Council,” rather

than the “HIV/AIDS Planning Council” or “Public Health – Seattle & King County.” Survey forms were bar coded for pre-paid reply.

To reach as broad a range of consumers as possible, survey distribution sites included 65 service agencies, community organizations, and health care facilities throughout the county. Surveys were also distributed at the offices of 34 private medical care providers and 11 private dentists. Public Health delivered a total of 2,700 surveys to the various agency and provider sites. Based on follow-up inquiries of agencies and providers, between 1,585 and 1,878 surveys were actually distributed to consumers. The Planning Council received a total of 538 valid responses, for a return rate of between 27% and 32%.

Efforts to reach traditionally underserved populations appeared to be successful. Survey demographic data indicate that 14% of respondents were women versus 9% of estimated King County PLWH, 27% of respondents were people of color versus 26% of PLWH estimates, and 12% of respondents identified heterosexual contact as the primary mode of HIV exposure versus 5% of PLWH estimates. The survey also appeared to be effective in reaching South and East King County PLWH, with 20% of respondents listing a non-Seattle zip code, comparable to estimates suggesting that 18% of King County PLWH live outside Seattle.

Additionally, 11% of respondents reported being homeless within the past year, 7% reported having been incarcerated within the past year and 30% of respondents reported having been diagnosed with a mental illness. Each of these percentages represents an increase over those reported by consumers on the 1999 survey.

As in previous years, however, two populations appear to have been under-represented among survey respondents: persons between 20-29 years of age (9% of survey respondents versus 23% of King County PLWH estimates) and heterosexual injection drug users (3% of respondents versus 7% of PLWH). Younger PLWH are less likely to know their serostatus, which may explain the low response rate among this cohort. The low percentage of self-identified injection drug users may represent under-sampling of this population or may indicate that respondents were not willing to disclose histories of substance use on the survey form. If the latter is true, this may correlate with the high percentage of respondents who reported heterosexual contact as their primary mode of transmission (12% of survey respondents versus 5% of PLWH estimates).

B. Provider Surveys

The Planning Council created and distributed a provider survey as another component of the 2001 assessment process. The Council believes that service provider data offers important comparisons to consumer-identified service priorities and gaps, as well as helping to gather input about sub-populations that may not have been effectively represented among consumer survey respondents. (See Appendix E for a copy of the provider survey instrument.)

The survey collected information from as broad a range as possible of providers of service to persons living with HIV/AIDS in King County as possible. These included primary care

providers, case managers, providers of non-Western therapies, private dentists, substance use and mental health treatment professionals and staff from human service agencies throughout King County.

Public Health distributed provider surveys at 59 agencies, community organizations, and health care facilities throughout the county. Surveys were also distributed to 40 private doctors and 11 private dentists.

The survey inquired about the type of service offered by the provider, the total number of persons with HIV/AIDS on the provider's current caseload, and demographic breakdowns related to the provider's HIV/AIDS clientele. Using the same list of 36 HIV/AIDS-related services that appeared on the consumer survey, providers were asked to identify up to seven services that they believed were most important for their client populations. The survey also asked providers to check each service that they felt was needed by a substantial number of their clients, but that clients were having trouble accessing, and to identify the top seven services that the provider believed helped his/her clients to access or maintain medical care.

Public Health delivered a total of 561 surveys to the various provider sites. The Planning Council received a total of 254 valid responses, for a return rate of 45%.

Efforts to reach providers of traditionally underserved populations were very successful. Survey responses indicate that 18% of the overall consumer population served by responding providers were female (versus 9% of estimated King County PLWH) and 29% of the clients served were people of color (versus 26% of PLWH estimates). Additionally, 37% of the providers' clients identified exposures other than male/male sex (versus 30% of PLWH estimates). Providers also reported seeing a higher percentage of youth and young adult PLWH (12% of the survey respondents' caseloads versus 1% of King County PLWH). Additionally, providers reported that an average of 15% of their clients had been homeless within the past year, 11% had been incarcerated within the past year, 46% had a history of chemical dependency and 37% had been diagnosed with a mental illness. These figures also represent increases from percentages reported by providers on the 1999 survey.

C. Consumer Focus Groups

The needs assessment process included eleven focus groups to gather in-depth qualitative information from specific sub-populations of persons living with HIV/AIDS in King County. The questions posed to participants focused on access to medical care (both at time of initial HIV diagnosis and currently), service needs, gaps in services, and overall impressions of the HIV/AIDS care service delivery system in King County. (See Appendix F for a copy of the focus group script.)

Focus groups were held with the following sub-populations of PLWH:

African Americans

Men who have sex with men (MSM)

East King County PLWH
Homeless persons
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Latinos (conducted in Spanish)
Native Americans

MSM/IDU
South King County PLWH
Women
Youth and young adults

The focus group strategy acknowledges that specific sub-populations of PLWH may present unique utilization patterns, access barriers and service gaps, and addresses the concern that written surveys might not be as well suited to capture information from members of several of the sub-populations. A total of 81 PLWH attended the eleven focus groups.

Based on input from providers of services to Asian/Pacific Islander PLWH, Public Health attempted to conduct one-on-one interviews with members of this population in lieu of a focus group. Providers noted that linguistic differences, as well as client concerns about safe-guarding their anonymity, make recruitment for a focus group extremely difficult. Unfortunately, only two Asian/Pacific Islander PLWH expressed interest in being interviewed. Because it would be difficult to generalize information from these individuals to the population of A/PI PLWH as a whole, the interviews were not conducted. Public Health will work with the Planning Council to explore potential means of gathering more useful data from this population in future assessments. As a result, information regarding service utilization and needs of A/PI PLWH are limited in this report to quantitative data from consumer surveys and key informant interviews of service providers to this population.

Service providers across the Continuum of Care disseminated information about the focus groups within the targeted communities, identified potential participants, and secured appropriate meeting spaces. Provider “hosts” were also invited to attend the focus group to assist in creating a safe environment for the participants. In five of the eleven groups, the providers felt that group members might be more candid without them present, and they chose not to remain after the initial introductions.

Participants received \$20 for their time, as well as reimbursement for transportation and/or child care expenses incurred. Staff recorded each of the groups on audiotape. In addition, a non-participant observer took written notes at each group to assist in the final transcription.

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In order to capture qualitative information about clientele and service trends, staff from Public Health – Seattle & King County interviewed 34 HIV/AIDS care service providers in King County. The providers supplied demographic information about their client population and identified trends or changes that they observed in their clientele. Providers also noted the types of HIV/AIDS-related care services that their clients most frequently utilized, as well as identified access barriers and system gaps in service delivery experienced by their clients. (See Appendix G for a copy of the provider interview form.)

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IV. General Findings from the Consumer and Provider Surveys

A. Distribution and Response

Consumer Surveys: Public Health delivered a total of 2,688 surveys to various sites throughout King County, including 65 service agencies and the offices of 34 private medical care providers and 11 private dentists. Based on follow-up inquiries, agencies and providers actually distributed approximately 1,550 surveys to consumers. The Planning Council received a total of 538 valid responses, for a return rate of 34.7%. This represents 9.6% of the estimated 5,625 persons living with HIV in the county who are presumed to be aware of their serostatus.

Distribution site codes on each survey allowed Public Health to track return rates. Table 3 shows a breakdown of survey returns by type of distribution site.

Table 3. Consumer Survey Returns by Distribution Site (N=538)

Type of Site	# Returned	% of Total
AIDS service organizations	284	53%
Medical center or hospital clinics	114	21%
Non-Western medical facilities	36	7%
Private doctor's offices	23	4%
Community health center or clinics	22	4%
AIDS residential care facilities	20	4%
Substance use recovery programs	11	2%
Other social service agencies	11	2%
Private dentist's offices	9	2%
Site code missing/removed	8	1%

Provider Surveys: Public Health delivered a total of 561 provider surveys to a wide spectrum of HIV/AIDS care providers throughout the county. These included primary care providers, case managers, mental health and substance use treatment professionals, non-Western care practitioners, private dentists and other social service providers. The Planning Council received a total of 256 valid responses, for a return rate of 46%.

The survey asked respondents to identify the nature of the specific service that they provided to persons living with HIV/AIDS. Table 4 shows a breakdown of surveys received from different types of providers.

Table 4. Provider Survey Returns by Provider Type (N=256)

Service Provided	# Returned	% of Total
Primary medical care	77	30%
Case management	32	13%
Mental health treatment/counseling	32	13%
Emotional support programs	19	7%
Housing related services	17	7%
Client advocacy services	17	7%
Substance use treatment/counseling	16	6%
Skilled nursing/hospice care	11	4%
Dental care	10	4%
Adult day health programs	9	2%
Volunteer support programs	7	3%
Alternative, non-Western therapies	6	2%
No answer	3	1%

B. Consumer Survey Demographics

In general, demographic responses on the consumer survey suggest a fairly representative sampling of persons living with HIV/AIDS (PLWH) in King County (Table 5). Survey response information was compared to PLWH demographic estimates generated by Public Health's HIV/AIDS Epidemiology Program to compare the respondents with the overall population of persons living with HIV in King County.

Although the Planning Council placed emphasis on collecting information from a wide range of persons living with HIV/AIDS, it also sought to over-sample traditionally under-served populations. These include homeless persons, PLWH with substance use histories, women, PLWH of color, youth/young adults and persons living with HIV/AIDS in South and East King County. Although the largest single response group was white MSM (60% of total), a higher proportion of persons of color, women, persons reporting heterosexual transmission, and non-Seattle King County residents responded to the survey than is represented among current King County HIV prevalence estimates.

Sex: Males accounted for 85% of the survey responses, females for 14% and transgendered persons for 1%. This represents a 14% increase in the percentage of female respondents from 1999. The overall prevalence estimates in King County are 91% male and 9% female.

Race: The survey asked respondents to check all applicable racial and ethnic categories. Response rates indicate that the survey sample was nearly identical to the racial distribution

among estimated King County PLWH. White PLWH comprised 71% of respondents, compared to 74% of estimated King County PLWH. Twelve percent of respondents identified as African-American (14% of estimated PLWH), 10% Latino/Latina (8% of estimated PLWH), 3% American Indian/Alaska Native (2% of estimated PLWH) and 2% Asian/Pacific Islander (2% estimated PLWH).

Age: Persons in the 25-29 age range are under-represented in survey responses (6% of respondents versus 13% of estimated PLWH), as are PLWH in their 30's (36% of respondents versus 47% of prevalence estimates). Conversely, persons between the ages of 40-49 are over-represented (32% versus 22%), as well as persons 50 and over (15% versus 6%). This may be due to several factors. Younger persons living with HIV are generally less likely to be aware of their serostatus than older individuals and thus would not have completed the survey. Providers of services to youth and young adults reported that younger PLWH are less likely to be actively engaged in the care system, and are also less likely to follow-up on paperwork. Despite outreach efforts, younger PLWH may not have received copies of the survey or may not have returned completed surveys.

Exposure category: The survey asked respondents to check all potential modes of transmission that they believe might have been responsible for their HIV infection. Reflective of epidemic patterns in King County, survey respondents were most likely to report HIV transmission due to male/male sexual activity (71%). Nine percent of respondents reported sharing drug needles as well as male/male sex. King County HIV prevalence estimates for these exposure categories are 70% MSM and 10% MSM/IDU.

Only 3% of respondents reported needle sharing exclusive of MSM activity, versus 7% of the King County PLWH estimates. A significantly greater percentage of survey respondents reported potential transmission risk through heterosexual contact than appears in case statistics (12% of respondents versus 5% of PLWH estimates; $p < .01$).

Annual income: No specific data exist regarding income levels of PLWH in King County against which to compare survey respondents. At least 68% of respondents are living at or below 200% of 2001 Federal Poverty Level guidelines (\$17,180 per year for a single individual), which is the cut-off point for eligibility for the majority of Ryan White CARE Act funded services in King County. This figure would probably be higher if household size were factored in, but the survey did not capture this information.

Place of residence: Seventy percent of survey respondents listed Seattle zip codes as their place of residence. Six percent of respondents listed East King County zip codes and 14% listed zip codes in South King County, similar to geographic prevalence estimates of 6% and 13%, respectively. This represents an 18% increase in the percentage of non-Seattle survey respondents from the 1999 needs assessment process.

HIV health status: Efforts to sample consumers across the spectrum of HIV disease appear to be successful. Thirty percent of respondents self-reported as being HIV+ without symptoms (representing a 25% increase in the percentage of HIV+ asymptomatic survey respondents from

1999), with an additional 16% identifying as being HIV+ and symptomatic. Twenty-seven percent of respondents stated that they had received an AIDS diagnosis based on low T-cell counts, with the remaining 26% reporting being AIDS diagnosed with an opportunistic infection.

Other demographic indicators:

- Eight percent of respondents reported having dependent children.
- Thirty percent of respondents reported having been diagnosed with a mental illness. (The survey did not ask the specific nature of the mental illness diagnosis.)
- Eleven percent reported being currently homeless or without a permanent place of residence within the past year.
- Seven percent reported being in jail or prison in the past year.
- Five percent reported using needles to inject street drugs in the past year.
- Fifteen percent reported using non-injectible street drugs in the past year.

Table 5. Demographic Comparison of 2001 Consumer Survey Respondents and King County PLWH Estimates (as of 4/01)

CHARACTERISTICS	CONSUMER SURVEY RESPONDENTS (N=538)		KC PLWH ESTIMATES (N=7,500)
SEX			
Male	456	(85%)	(91%)
Female	75	(14%)	(9%)
Transgendered (M-to-F)	6	(1%)	N/A
Transgendered (F-to-M)	0	(0%)	N/A
No response	0	(0%)	N/A
RACE*			
African-American	62	(12%)	(14%)
American Indian/Alaska Native	14	(3%)	(2%)
Asian/Pacific Islander	13	(2%)	(2%)
Caucasian	380	(71%)	(74%)
Latino/Latina	52	(10%)	(8%)
Other	2	(<1%)	(<1%)
No response	12	(2%)	N/A
AGE			
<13	1	(<1%)	(<1%)
13-24	19	(4%)	(11%)
25-29	31	(6%)	(13%)
30-39	191	(36%)	(47%)
40-49	174	(32%)	(22%)
50 and over	82	(15%)	(6%)
No response	40	(7%)	N/A
EXPOSURE CATEGORY*			
Male/male sex (non-IDU)	382	(71%)	(70%)
Injection drug use (non-MSM)	16	(3%)	(7%)
IDU and male/male sex	49	(9%)	(10%)
Heterosexual contact	62	(12%)	(5%)
Transfusion/blood products	24	(4%)	(1%)
Parent at risk/has HIV	2	(<1%)	(<1%)
Other/unknown	49	(8%)	(7%)
No response	9	(2%)	N/A

*Respondents were asked to check all applicable answers. Totals are greater than 100%.

Table 5 (Continued)

CHARACTERISTICS	CONSUMER SURVEY RESPONDENTS (N=538)		KC PLWH ESTIMATES (N=7,500)
ANNUAL INCOME			
Less than \$8,500	211	(39%)	N/A
\$8,501-\$17,000	155	(29%)	N/A
\$17,001-\$25,000	59	(11%)	N/A
\$25,001-\$30,000	33	(6%)	N/A
\$30,001-\$40,000	24	(5%)	N/A
Over \$40,000	45	(8%)	N/A
No response	11	(2%)	N/A
PLACE OF RESIDENCE			
Seattle	378	(70%)	(81%)
East King County	33	(6%)	(6%)
South King County	74	(14%)	(13%)
No response	53	(10%)	N/A
HIV STATUS			
HIV+, without symptoms	160	(30%)	HIV+: 67%
HIV+, with symptoms	85	(16%)	
AIDS diagnosed, by T-cell count	147	(27%)	AIDS dx: 33%
AIDS diagnosed, by OI	141	(26%)	
No response	5	(1%)	
OTHER DEMOGRAPHIC CHARACTERISTICS			
Have dependent children	42	(8%)	N/A
Ever diagnosed with mental illness	162	(30%)	N/A
In past year:			
Homeless	58	(11%)	N/A
In jail or prison	35	(7%)	N/A
Used needles to inject drugs	44	(8%)	N/A
Used other street drugs	81	(15%)	N/A

C. Provider Survey Demographics

The survey asked providers about the total number of clients with HIV/AIDS on their active caseload and asked them to characterize their HIV/AIDS clientele by several demographic indicators. Averaging valid responses from all returned surveys derived percentages for each of the demographic characteristics. Based on response to these demographic questions, it appears that the client population served by providers survey respondents is fairly representative of PLWH in King County (Table 6). Efforts to over-sample among providers of services to women, persons of color and non-MSM proved successful based on demographic frequencies.

Total caseload: The average caseload reported by providers is 51 clients, with a range of one to 600. Primary medical care providers (n=77) reported average caseloads of 55 clients, with a range of two to 350 and a median of 27 clients. Case managers (n=32) reported an average caseload of 50 clients, with a range of two to 134 and a median caseload of 42 clients.

Sex: The average client caseload among responding providers was 82% male, 18% female and 1% transgendered. HIV prevalence estimates in King County are 91% male and 9% female.

Race: The racial breakdown of the average provider caseload was 71% white and 26% persons of color, as compared to King County PLWH estimates of 74% and 26%, respectively. Within non-white categories, provider caseload percentages and King County estimates were relatively similar, with providers reporting that 15% of their client were African-American (KC estimate: 14%), 8% Latino/Latina (KC estimate: 8%), 2% American Indian/Alaska Native (KC estimate 2%) and 1% Asian/Pacific Islander (KC estimate: 2%).

Age: Unlike consumer survey percentages, provider caseloads were more likely to over-represent young adult clients and somewhat less likely to represent PLWH between the ages of 25-39. Less than one percent of clients served were under the age of 13, similar to King County PLWH estimates. Twelve percent of provider caseloads were between the ages of 13-24, similar to County estimates of 11%. Eighteen percent of clients were between 20-29 years of age (KC estimate: 13%), 42% between 30-39 (KC estimate: 45%) and 28% over 40 years of age (KC estimate: 28%).

Exposure category: The survey asked providers to classify their clients by primary modes of HIV exposure. Providers reported that 63% of their clients were exposed through male/male sex, with an additional 9% of clients dually exposed through MSM contact and injection drug use. King County PLWH estimates for these populations are 70% and 10%, respectively. Providers reported that 15% of their clients were primarily exposed through injection drug use (KC estimate: 7%). Similar to the consumer survey, providers reported higher percentages of clients exposed through heterosexual contact (11%) than are represented in King County PLWH estimates (5%).

Annual income: Providers reported that an average of 80% of their clients are living at or below 200% of Federal Poverty Level, with 51% earning less than 100% of FPL. As with the consumer survey, this figure would actually be higher if household size were factored in, but the survey did

not capture this information.

Place of residence: Providers reported seeing clients whose distribution throughout the county was fairly similar to King County PLWH estimates. Seventy-seven percent of clients are from Seattle (KC estimate: 81%), 6% from East King County (KC estimate: 6%) and 10% from South King County (KC estimate: 13%). The remaining 6% of clients served reside outside King County, but receive service from King County-based providers.

Primary language: Providers reported that 94% of their clients are primarily English speaking, with 5% identifying Spanish as their primary language. This represents almost a twofold increase from the 1999 survey in the percentage of Spanish-speaking clients. Seventeen percent of all responding providers noted that at least one of their clients spoke a primary language other than English or Spanish, representing 1% of all consumers served. The most frequently spoken languages for these consumers are Amharic (and other African languages) and a variety of Southeast Asian languages.

Other demographic indicators: On average, providers reported higher percentages of other medical or social co-morbidities than in 1999. In 2001, providers reported that:

- Forty-seven percent of their clients have been diagnosed with a mental illness (up from 32% from 1999 provider reports)
- Forty-six percent have a history of chemical dependency (up from 40% in 1999)
- Fifteen percent are currently homeless or have been without a permanent place of residence within the past year (up from 10% in 1999)
- Eleven percent have been in jail or prison in the past year (up from 8% in 1999).

Table 6. Demographic Comparison of 1999 Provider Survey Client Demographics and King County PLWH Estimates (as of 4/01)

Characteristics	Client Demographics From Provider Surveys (N=256)	KC PLWH Estimates (N=7,500)
Average client caseload = 51		
SEX		
Male	82%	91%
Female	18%	9%
Transgendered (M-to-F)	<1%	N/A
Transgendered (F-to-M)	<1%	N/A
RACE		
African-American	15%	14%
American Indian/Alaska Native	2%	2%
Asian/Pacific Islander	1%	2%
Caucasian	71%	74%
Latino/Latina	8%	8%
Other	2%	N/A
AGE		
<13	<1%	<1%
13-24	12%	11%
20-29	18%	13%
30-39	42%	47%
40 and over	28%	28%
EXPOSURE CATEGORY		
Male/male sex	63%	70%
Injection drug use (non-MSM)	15%	7%
IDU and male/male sex	9%	10%
Heterosexual contact (non-IDU)	11%	5%
Transfusion/blood products	1%	1%
Parent at risk/has HIV	<1%	<1%
Other	<1%	6%
ANNUAL INCOME		
Under 100% of FPL	51%	N/A
101-200% of FPL	29%	N/A
201-300% of FPL	12%	N/A
Over 300% of FPL	8%	N/A

Table 6 (Continued)

Characteristics	Client Demographics From Provider Surveys (N=256)	KC PLWH Estimates (N=7,500)
PLACE OF RESIDENCE		
Seattle	77%	81%
East King County	6%	6%
South King County	10%	13%
Outside King County	6%	N/A
PRIMARY LANGUAGE		
English	94%	N/A
Spanish	5%	N/A
Other	1%	N/A
OTHER DEMOGRAPHIC CHARACTERISTICS		
Homeless (in past year.)	15%	N/A
In jail or prison (in past year)	11%	N/A
Hx. of chemical dependency	46%	N/A
Diagnosed w/mental illness	47%	N/A

D. Medical Care Access

Ninety-three percent of survey respondents reported current use of ambulatory medical care. This figure is identical to the response from the 1999 surveys. Only 1% of survey respondents (6 out of 538) reported that they needed, but could not medical care.

An additional 5% of respondents (n=24) identified outpatient medical care as a service that they did not need. Of these 24 individuals, one-third reported that their viral loads were undetectable and almost three-quarters reported currently taking protease inhibitors and/or antiviral medications. This suggests that these consumers have had at least some contact with medical professionals regarding their HIV disease, although they may not consider themselves to be currently using the service.

Women were somewhat less likely than men to report utilization of primary medical care during the past year (89% versus 93%), although this finding is not statistically significant. No other statistically significant differences emerged regarding utilization of medical care based on other demographic factors.

Seventy-nine percent of consumers reported currently taking some form of antiviral medications. (Table 7) This represents a statistically significant increase from 69% of consumers who reported taking antiviral medications on the 1999 survey. However, the percent of consumers who report taking protease inhibitors and other drugs to treat or prevent opportunistic infections has

decreased significantly in the past two years. Based on input from consumers in focus groups and key informant interviews with providers, it appears that the decrease in the percentage of PLWH on protease inhibitors is related to clients choosing to no longer take these medications after having been taking them for several years, as well as clients deciding to discontinue medications due to negative side effects.

Table 7: Current Medication Status

CONSUMERS CURRENTLY TAKING HIV-RELATED MEDICATIONS:			
	2001 (N=538)		1999
On antiviral medications	423	79%	69%
On protease inhibitors	285	53%	60%
On other drugs to treat/prevent OI	229	43%	51%

E. Service Utilization

Overall service utilization: The consumer survey inquired about 36 types of HIV/AIDS-related services offered in the King County Continuum of Care. Consumers identified each service either as one that they needed and used, did not need, or needed but could not get. Utilization rates were calculated based on services which consumers checked as “need and use.”

In order to make the data more useful in making funding decisions, responses were collapsed into the 22 Planning Council-identified Ryan White service categories for analysis and reporting. This was necessary because several Ryan White service categories include component services (e.g., the Ryan White category of “Counseling (Emotional Support)” includes one-on-one peer support, support groups and spiritual and religious counseling). (See Appendix G for a breakdown of the specific services associated with each Ryan White eligible service category.) Cumulative responses by service category are reported in Table 8.

As in previous years, utilization of most services increased with the person’s level of illness. In particular, consumers who were AIDS diagnosed used programs that provide assistance with activities of daily living at higher rates than asymptomatic PLWH. These include food and meal programs (56% versus 33%), volunteer home chore services (17% versus 7%) and transportation services (37% versus 25%). Persons with AIDS diagnoses were also significantly more likely than asymptomatic consumers to use case management (86% versus 68%), peer counseling (62% versus 46%), housing assistance (51% versus 33%) and emergency financial assistance (48% versus 32%). Utilization rates for ambulatory medical care and prescription drug programs were similar among the two groups. In general, PLWH who were HIV+ and symptomatic displayed utilization rates somewhere between the other two groups.

Table 8. Service Utilization from Consumer Surveys (N=538)

Rank	Service	Responses	%
1	Ambulatory/outpatient medical care	499	93%
2	Client advocacy	448	83%
3	Case management	425	79%
4	Dental care	383	71%
5	Insurance programs	307	57%
6	Counseling (emotional support)	302	56%
7	Drug prescription program (ADAP)	285	53%
8	Mental health therapy/counseling	261	49%
9	Food/meals	256	48%
10	Referral	250	46%
11	Housing assistance/related services	238	44%
12	Direct emergency financial assistance	222	41%
13	Alternative, non-Western therapies	211	39%
14	Transportation	178	33%
15	Legal assistance	174	32%
16	Treatment adherence support	161	30%
17	Health education/risk reduction	99	18%
18	Home health care	97	18%
19	Substance use treatment/counseling	86	16%
20	Adult day health	85	16%
21	Volunteer home chore	66	12%
22	Child care	16	3%

Additional Utilization Data by Categories:

Alternative/non-Western therapies: Almost all of the consumers who are currently using alternative therapies are also receiving Western medical care (204 out of 211; 97%). Consumers who reported using alternative therapies were also asked if they considered it to be their primary form of medical care. Of those using alternative therapies, 15% (32 out of 211) stated that they consider non-Western therapies as their primary source of medical care.

Client Advocacy: A high percentage of consumers reported using one or more of the various

components of client advocacy (88%). Within the client advocacy category, the component service that was most frequently used by consumers was medical information about HIV/AIDS (used by 74% of respondents). Thirty-three percent of respondents reported using non-case management peer advocacy services, 30% reported using benefits counseling and 7% of respondents reported currently using interpreter services.

Counseling (emotional support): Among the component services included in this category, consumers reported highest utilization of support groups (used by 41% of respondents) and one-on-one peer support (33%). Twenty-six percent of respondents reported using spiritual and religious counseling.

Direct emergency financial assistance: Among the component services included in this category, approximately equal numbers of consumers reported receiving help paying for groceries (32%) and help paying for utilities (31%). .

Food/meals: Among the component services included in this category, twice as many consumers reported using food bank/free groceries services (42%) as reported receiving home-delivered meals (21%).

Comparison Between 1999 and 2001 Service Utilization: Utilization rates remained fairly constant in approximately two-thirds of service categories between 1999 and 2001. The percentage of consumers who reported using each service remained virtually unchanged in 9 of the 20 comparable service categories (an increase or decrease of 3 percentage points or less). (Table 9).

Utilization of several types of services increased from 1999 to 2001. These included case management, insurance programs, transportation and mental health therapy:

- The increase in consumers who reported using case management and transportation may be due to demographic changes, both within the overall population of PLWH and among survey respondents. Utilization of case management tends to be higher among persons of color and injection drug using PLWH, two populations that increased in the overall AIDS case figures and among survey respondents.
- The increase in PLWH who are using insurance programs is offset by a slight decrease in those who reported using the Washington State AIDS drug assistance program (ADAP). This may signal that consumers are enrolling in programs that offer comprehensive medical and prescription drug benefits, and are somewhat less dependent on ADAP to primarily cover the costs of their medications.

Table 9. Comparison Between 1999 and 2001 Service Utilization

Service	1999 % (N=509)	2001 % (N=538)
Adult day health	11%	16%
Alternative/non-Western therapies	36%	39%
Ambulatory/outpatient medical care	92%	93%
Case management	72%	79%
Child care	2%	3%
Client advocacy	82%	83%
Counseling (emotional support)	57%	56%
Dental care	70%	71%
Direct emergency financial assistance	46%	41%
Drug prescription programs (ADAP)	57%	53%
Food/meals	51%	48%
Home health care	18%	18%
Housing assistance/related services	42%	44%
Insurance programs	50%	57%
Legal assistance	37%	32%
Mental health therapy/counseling	43%	49%
Referral	52%	46%
Substance use treatment/counseling	13%	16%
Transportation	26%	33%
Volunteer home chore	15%	12%

- A somewhat higher percentage of 2001 survey respondents reported having been diagnosed with a mental illness than in 1999 (30% versus 26%). In addition, providers reported much higher percentages of their caseloads being diagnosed with mental illness (47% in 2001 versus 32% in 1999). These figures, coupled with increased availability of Ryan White-funded mental health services, may explain the increased utilization of these services.

No service category demonstrated a significant decrease in utilization during the past two years, although use of telephone referrals to dental and medical care and legal assistance decreased somewhat. Tighter eligibility criteria for direct emergency financial assistance also seem to have resulted in somewhat lower consumer utilization of this service.

F. Service Priorities

Consumer-identified priorities: The consumer survey included a one-page list of the 36 types of HIV/AIDS-related services offered in the King County Continuum of Care. The survey asked consumers to identify up to seven services that they considered as most important to them. Responses were collapsed into the 22 Planning Council-identified Ryan White service categories shown below, and ranked by overall percentage of response. Table 10 includes cumulative responses of service priorities (services which consumers rated as one of their seven most important services).

Consumers ranked ambulatory medical care as the highest service priority, with almost two-thirds of respondents stating that it was a priority for them. Medical care was followed by dental care, case management, housing assistance, insurance programs and drug prescription programs as the top service priorities.

The percentage difference between each of the top three service priorities (ambulatory medical care, dental care and case management) are all statistically significant, as are the difference between the services ranked fourth and fifth (housing and insurance programs). While these differences suggest a clear demarcation in consumer priority rankings, the services ranked eighth through twelfth are relatively equal in the percentage of consumers identifying them as service priorities.

Level of illness (HIV+ asymptomatic, HIV+ with symptoms or AIDS diagnosed) appears to have relatively little impact on the ways in which consumers prioritized most services. This applies both to the actual rank order of the services, as well as to the relative importance of the service based on the percentage of those who reported it as a priority.

Consumers with AIDS diagnoses were generally more likely than asymptomatic respondents to prioritize assistance with activities of daily living (food and meals: 33% versus 18%; transportation: 18% versus 8%; volunteer home chore: 10% versus 4%; and home health care: 12% versus 6%). Persons with AIDS diagnoses were also more likely to prioritize case management (53%) than either HIV+, asymptomatic persons (41%) or HIV+ respondents with symptoms (42%).

Dental care was the sole service that was significantly more likely to be prioritized by HIV+ asymptomatic consumers. Dental care was ranked as a service priority by 66% of these individuals, versus 42% of HIV+ persons with symptoms and 48% of those with AIDS diagnoses.

**Table 10. Service Priorities from Consumer Surveys
(N=511; 27 missing/invalid responses)**

Rank	Service	Total Votes	%
1	Ambulatory/outpatient medical care	324	63%
2	Dental care	284	56%
3	Case management	256	50%
4	Housing assistance/related services	241	47%
5	Insurance programs	209	41%
6	Drug prescription program (ADAP)	202	40%
7	Client advocacy	181	35%
8	Direct emergency financial assistance	156	31%
9	Alternative, non-Western therapies	147	29%
10 (tie)	Food/meals	146	29%
10 (tie)	Mental health therapy/counseling	146	29%
12	Counseling (emotional support)	141	28%
13	Legal assistance	80	16%
14	Transportation	72	14%
15	Adult day health	52	10%
16	Referral	50	10%
17	Home health care	48	9%
18	Substance use treatment/counseling	45	9%
19	Volunteer home chore	39	8%
20	Treatment adherence support	29	6%
21	Health education/risk reduction	21	4%
22	Child care	11	2%

Comparison between 1999 and 2001 consumer service priorities: Relative service priority rankings changed little between 1999 and 2001 (Table 11). Only three of the twenty comparable service categories moved three or more places up or down in overall consumer priority rankings over the past two years. (Health education/risk reduction and treatment adherence support were not included on the 1999 consumer survey.)

**Table 11. Comparison Between 1999 and 2001
Consumer-Identified Service Priorities**

Service	1999 (N=503)		2001 (N=511)	
	Rank	%	Rank	%
Adult day health	17 (tie)	9%	15	10%
Alternative/non-Western therapies	10	28%	9	29%
Ambulatory/outpatient medical care	3	55%	1	63%
Case management	4	51%	3	50%
Child care	20	2%	22	2%
Client advocacy	7	35%	7	35%
Counseling (emotional support)	11	27%	12	28%
Dental care	2	55%	2	56%
Direct emergency financial assistance	9	34%	8	31%
Drug prescription programs (ADAP)	1	62%	6	40%
Food/meals	6	35%	10 (tie)	29%
Home health care	15 (tie)	10%	17	9%
Housing assistance/related services	5	47%	4	47%
Insurance programs	8	34%	5	41%
Legal assistance	13	21%	13	16%
Mental health therapy/counseling	12	23%	10 (tie)	29%
Referral	15 (tie)	10%	16	10%
Substance use treatment/counseling	19	7%	18	9%
Transportation	14	13%	14	14%
Volunteer home chore	17 (tie)	9%	19	8%

NOTE: The categories of “Health Education/Risk Reduction” (ranked 21st in 2001) and “Treatment Adherence Support” (ranked 20th in 2001) were not included on the 1999 consumer survey. As a result, cross-year comparisons are not possible.

Drug prescription programs, ranked as the top consumer priority in 1999, dropped to the sixth highest priority (ranked as a priority by 62% of consumers in 1999 and 40% in 2001).

Conversely, consumers were more likely in 2001 to prioritize insurance programs, which moved up from eighth to fifth in the priority rankings (1999: 34%; 2001: 41%). Based on information from consumer focus group participants and providers of services, it appears that reasons for these changes are two-fold: the continuing decline in private insurance options in Washington State and growing awareness of the need to ensure comprehensive medical coverage for PLWH, not just prescription drug access.

Food and meal programs dropped from the sixth highest priority in 1999 (35% listing the service as a priority) to a tie for tenth in 2001 (29%). This may be a result of the increased percentage of HIV+ asymptomatic respondents to the survey, many of whom are less dependent than disabled consumers on having this service provided.

In addition to the aforementioned services, three other categories experienced significant changes in the overall percentage of consumers who listed them as priorities between the two survey years. These included ambulatory medical care, legal assistance and mental health therapy/counseling. Sixty-three percent of respondents prioritized ambulatory care in 2001, up from 55% in 1999. The percent of consumers who prioritized mental health therapy also increased, from 23% in 1999 to 29% in 2001. Legal assistance was significantly less likely to be listed as a priority, dropping from 21% of respondents in 1999 to 16% in 2001.

Provider-identified service priorities: The provider survey included the same one-page list of 36 types of HIV/AIDS-related services as was included in the consumer version. The survey asked each responding provider to identify up to seven services that they considered as most important for the clients they served. Responses were collapsed into the 22 Planning Council-identified Ryan White service categories for analysis and reporting purposes. Table 12 reports cumulative responses of provider priorities. (In order to insure that provider-identified priorities were not biased by over-sampling certain types of providers (i.e., medical providers and case managers), additional data runs were conducted controlling for provider type. Analysis revealed that provider type did not significantly skew identification of priorities or gaps.)

Providers ranked ambulatory care as the highest service priority for their clients, followed by case management, mental health therapy/counseling, drug prescription programs, and substance use treatment/counseling.

**Table 12. Service Priorities from Provider Surveys
(N=251; 5 missing/invalid responses)**

Rank	Service	Total Votes	%
1	Ambulatory/outpatient medical care	191	76%
2	Case management	170	68%
3	Mental health therapy/counseling	158	63%
4	Drug prescription program (ADAP)	137	55%
5	Substance use treatment/counseling	123	49%
6	Housing assistance/related services	103	41%
7	Client advocacy	98	39%
8	Treatment adherence support	68	27%
9	Counseling (emotional support)	63	25%
10	Insurance programs	57	23%
11 (tie)	Transportation	54	22%
11 (tie)	Dental care	54	22%
13	Adult day health	45	18%
14	Home health care	40	16%
15	Food/meals	29	12%
16 (tie)	Alternative, non-Western therapies	25	10%
16 (tie)	Health education/risk reduction	25	10%
18	Direct emergency financial assistance	24	10%
19	Legal assistance	22	9%
20	Volunteer home chore	13	5%
21 (tie)	Child care	4	2%
21 (tie)	Referral	4	2%

Comparison between 1999 and 2001 provider-identified service priorities: Relative service priority rankings changed little between 1999 and 2001 (Table 13). Similar to the consumer surveys, only three of the twenty comparable service categories moved three or more places up or down in priority rankings over the past two years, and none of these were among the top nine services prioritized by providers. (Health education/risk reduction and treatment adherence support were not included on the 1999 provider survey.)

**Table 13. Comparison Between 1999 and 2001
Provider-Identified Service Priorities**

Service	1999 (N=216)		2001 (N=251)	
	Rank	%	Rank	%
Adult day health	13	18%	13	18%
Alternative/non-Western therapies	16	13%	15	10%
Ambulatory/outpatient medical care	3	69%	1	76%
Case management	1	72%	2	68%
Child care	19	3%	21 (tie)	2%
Client advocacy	6	46%	7	39%
Counseling (emotional support)	8	32%	9	25%
Dental care	9	29%	11 (tie)	22%
Direct emergency financial assistance	10	26%	18	10%
Drug prescription programs (ADAP)	2	70%	4	55%
Food/meals	11	19%	16	12%
Home health care	15	14%	14	16%
Housing assistance/related services	7	38%	6	41%
Insurance programs	14	16%	10	23%
Mental health therapy/counseling	5	53%	3	63%
Substance use treatment/counseling	4	57%	5	49%
Transportation	12	19%	11 (tie)	22%
Volunteer home chore	18	4%	20	5%

NOTE: The categories of “Health Education/Risk Reduction” (ranked 21st in 2001) and “Treatment Adherence Support” (ranked 20th in 2001) were not included on the 1999 provider survey. As a result, cross-year comparisons are not possible.

Insurance programs demonstrated the greatest upward movement in ranking, rising from fourteenth highest priority (16% of providers listing this service as a priority in 1999) to tenth in 2001 (23%). Two services dropped significantly in the rankings during the past two years: direct emergency financial assistance dropped from tenth priority (26%) to eighteenth (10%) and food/meals fell from eleventh (19%) to sixteenth (12%).

In addition to the aforementioned services, two other categories experienced significant changes in the overall percentage of providers who listed them as priorities. These included drug prescription programs (noted as a priority by 70% of providers in 1999 and 55% in 2001) and mental health therapy/counseling (53% in 1999; 63% in 2001). Providers seem to concur with

consumers regarding the increasing priority of comprehensive insurance coverage, as well as continuing to support coverage of state-administered drug programs. Providers noted that increasing percentages of their caseloads are persons with diagnoses of mental illness, leading to an increase in the percentage of providers who prioritized mental health treatment for their clients.

Comparison between 2001 consumer and provider service priorities: Comparisons between consumer and provider responses yield numerous differences in both priority rankings and percentages. Statistically significant differences emerged in almost two-thirds of all services under consideration. In general, providers were more likely to prioritize clinical services, while consumers were more likely to prioritize ancillary services, particularly those that provide financial and in-home support.

Significant disparities are visible even in those service categories that both consumers and providers rank among their top priorities. Although both groups assign high priority to primary medical care (ranked first by both consumers and providers), case management (consumer rank: 3; provider rank: 2) and housing services (consumer rank: 4; provider rank: 6), the relative importance placed on these services is quite different. The disparity is greatest in the area of case management, with 68% of providers ranking it as a service priority, versus 50% of consumers. Significant differences are also present in the percent prioritizing outpatient medical care (76% of providers versus 63% of consumers).

Since the inception of the comprehensive assessment process in 1995, providers have been far more likely than consumers to identify substance use treatment and mental health counseling as service priorities. This trend continues in 2001, with even greater disparity between the two groups. Providers were over five times more likely than consumers to prioritize substance use treatment (49% versus 9%) and over twice as likely to prioritize mental health counseling (63% versus 29%). These discrepancies were also noted by providers during the key informant interview process, many of whom reported increases in the incidence of dual and triple diagnoses (HIV/mental illness/chemical dependency) among their client populations, coupled with consumer resistance to and/or lack of access to these services.

Providers were also significantly more likely to prioritize the new category of treatment adherence support for their clients (27% versus 6%). As noted in key informant interviews, providers stated that mental illness and substance use often pose the greatest barriers to consumers' ability to maintain their treatment regimens. Thus, consumers who refuse mental health and/or substance use treatment may also not recognize treatment adherence support as an important component of their medical care.

Consumers were significantly more likely than providers to assign priority to alternative/non-Western therapies (29% versus 10%), dental care (56% versus 22%), direct emergency financial assistance (31% versus 10%), and food and meal programs (29% versus 12%). Previous needs assessments revealed similar disparities, and the percentage difference between consumer and provider perceptions of these services has not lessened.

Continuing a trend first noted in 1999, a significant disparity exists between consumer and provider prioritization of insurance programs, with consumers being significantly more likely to prioritize the service (34% versus 16%; $p < .01$). This may be due to gathering responses from a diverse group of provider types. Provider survey respondents who are not in a clinical or case management setting may be unaware of the ways in which their particular clients pay for medical care and may not see insurance as a priority when related to the specific service they provide.

G. Service Gaps

Consumer-identified service gaps: As previously stated, consumers identified each of the 36 services offered in the King County Continuum of Care as ones that they needed and used, did not need, or needed but could not get. Each service that a consumer identified as “needed, but could not get” is considered a service gap. These responses were collapsed into the 22 Planning Council-identified Ryan White service categories for analysis and reporting purposes. Cumulative categorical service gap responses appear in Table 14.

As shown in the table, consumers identified very few of the services available in the Seattle-King County Continuum of Care as being grossly deficient. Several differences emerged, however, when comparing responses among specific sub-populations. (These will be discussed in the population-specific information found in Section V.)

Consumers considered lack of emergency financial assistance as the number one service gap. Almost one quarter of survey respondents noted this gap. Among the sub-components of this service category, 19% of respondents identified a gap in assistance with utility bills and 18% identified a gap in help paying for groceries. These results are not surprising, given the very low income levels reported by a large percentage of the survey population. Providers noted that, for many of their clients, financial problems such as these pre-date the clients’ HIV diagnosis and are further complicated by the onset of disease.

Twenty-two percent of survey respondents noted a gap in the provision of alternative, non-Western therapies. Among the component parts of this category, 18% noted a gap in access to naturopathy and herbal medicine and 14% noted a gap in acupuncture/Chinese medicine services. Based on information from service providers and consumers in focus groups, PLWH continue using these services to alleviate pain and other physical symptoms, and lessen the side effects of HIV-related medications. Service gaps exist for consumers who are not able to afford the services (due to lack of insurance coverage for non-Western medical services or having incomes above Ryan White eligibility levels) or because the services are not geographically accessible.

Table 14. Service Gaps from Client Surveys (N=538)

Rank	Service	Total Votes	%
1	Direct emergency financial assistance	130	24%
2	Alternative, non-Western therapies	121	22%
3	Counseling (emotional support)	107	20%

4	Client advocacy	105	20%
5	Housing assistance/related services	103	19%
6	Dental care	81	15%
7	Legal assistance	57	11%
8	Mental health therapy/counseling	56	10%
9	Food/meals	54	10%
10	Referral	49	9%
11	Volunteer home chore	36	7%
12	Insurance programs	33	6%
13 (tie)	Adult day health	27	5%
13 (tie)	Home health care	27	5%
15	Treatment adherence support	26	5%
16	Drug prescription program	25	5%
17	Case management	24	4%
18	Substance use treatment/counseling	20	4%
19	Transportation	18	3%
20	Health education/risk reduction	14	3%
21 (tie)	Ambulatory/outpatient medical care	6	1%
21 (tie)	Child care	6	1%

Other top five ranked service gaps include counseling (peer emotional support), client advocacy and housing assistance. Within the counseling (emotional support) category, one-to-one peer support was the largest gap (identified as a gap by 14% of consumers), followed by support groups (12%) and spiritual and religious counseling (7%). Within the client advocacy category, the greatest gaps were reported in the areas of benefits counseling (other than by a case manager) (11%) and peer or client advocacy (10%). Only 5% of respondents identified gaps in accessing medical information about HIV/AIDS, while 1% of respondents identified a gap in accessing interpreter services. As regards the components of housing assistance, 14% of consumers reported difficulty in getting help paying rent and 13% reported a gap in help finding low income housing.

As in 1999, few significant differences emerged in service gap identification based on level of illness. In 1997, persons who were HIV+ and symptomatic were almost twice as likely as other consumers to identify gaps in service provision in almost all categories. This year, HIV+, symptomatic consumers were no more likely than either HIV+ asymptomatic or AIDS-diagnosed persons to note gaps in services.

The sole category in which a statistically significant distinction based on level of illness was housing related services. Twenty-nine of HIV+ asymptomatic respondents identified at least one of the components of housing assistance as a service they needed, but could not get, as opposed to 20% of HIV+ symptomatic and 14% of persons with AIDS diagnoses. Based on guidance from the HIV/AIDS Housing Committee, AIDS-defining disability remains one of the eligibility criteria for placement in permanent and transitional AIDS housing. This is due largely to resource limitations in the number of units available within the HIV system, and a critical housing issue in King County in general. As a result, consumers who are not disabled by their HIV, while they are eligible for rental assistance and placement in emergency shelter, may be more likely to identify a gap in their access to permanent and transitional housing.

Comparison between 1999 and 2001 consumer-identified service gaps: Very few significant changes emerged between consumer-identified service gaps from 1999 to 2001 (Table 15). Based on input from participants in focus groups, it appears that this is due to several factors, depending on the service category. In some instances, this may suggest an insurmountable, ongoing gap, such as with financial assistance, in which Ryan White funds are incapable of fulfilling consumer need. In others, such as counseling/emotional support, it may suggest that a prior gap has been filled, but a new gap has developed in an emerging consumer sub-population such as the one identified in 2001 by Latino men.

The sole significant increase in identified gaps occurred in the category of client advocacy. The service ranked as the 10th highest gap in 1999, with 8% of consumers identifying lack of access to one or more of the sub-components of this category (benefits counseling other than by a case manager, medical information about HIV/AIDS, interpreter services and peer or client advocacy). In 2001, client advocacy rose to the number four gap, with 20% of consumers identifying a service gap in this category. A growing gap in benefits counseling accounts for this increase, particularly as more low income and non-resident consumers are accessing services.

Although housing remains among the top five service gaps identified by consumers, the percentage of consumers who identified access gaps in housing assistance and related services decreased from 24% in 1999 to 19% in 2001. This may be due to Planning Council decisions about increasing the pool of emergency rental assistance funds available to consumers, since the percentage of consumers who reported current homelessness during the past two survey periods has not increased significantly.

**Table 15. Comparison Between 1999 and 2001
Consumer-Identified Service Gaps**

Service	1999 % (N=509)	2001 % (N=538)
Adult day health	6%	5%
Alternative/non-Western therapies	25%	22%
Ambulatory/outpatient medical care	1%	1%

Case management	5%	4%
Child care	2%	1%
Client advocacy	8%	20%
Counseling (emotional support)	19%	20%
Dental care	17%	15%
Direct emergency financial assistance	24%	24%
Drug prescription programs (ADAP)	6%	5%
Food/meals	12%	10%
Home health care	5%	5%
Housing assistance/related services	24%	19%
Insurance programs	9%	6%
Legal assistance	11%	11%
Mental health therapy/counseling	13%	10%
Referral	7%	9%
Substance use treatment/counseling	2%	4%
Transportation	7%	3%
Volunteer home chore	8%	7%

NOTE: The categories of “Health Education/Risk Reduction” (reported as a gap by 3% of consumers in 2001) and “Treatment Adherence Support” (reported as a gap by 5% of consumers in 2001) were not included on the 1999 consumer survey. As a result, cross-year comparisons are not possible.

Provider-identified service gaps: The provider survey asked respondents to identify service gaps for the clients they served using the same list of HIV/AIDS-related services from which priorities were identified. Each responding provider was asked to check any of the services which a substantial number of their clients needed, but had difficulty in accessing. Responses were collapsed into the 22 Planning Council-identified Ryan White service categories for analysis and reporting purposes. Table 16 includes cumulative responses of provider-identified service gaps.

Table 16. Service Gaps from Provider Surveys (N=253)

Rank	Service	Total Votes	%
1	Housing assistance/related services	112	44%
2	Substance use treatment/counseling	81	32%
3	Mental health therapy/counseling	77	30%
4	Client advocacy	71	28%

5	Dental care	69	27%
6	Counseling (emotional support)	63	25%
7	Transportation	58	23%
8	Treatment adherence support	53	21%
9	Direct emergency financial assistance	45	18%
10	Insurance programs	44	17%
11	Home health care	36	14%
12	Alternative, non-Western therapies	35	14%
13	Legal assistance	34	13%
14	Drug prescription program	32	13%
15	Adult day health	31	12%
16	Case management	28	11%
17	Ambulatory/outpatient medical care	26	10%
18	Food/meals	25	10%
19	Volunteer home chore	23	9%
20	Child care	16	6%
21	Health education/risk reduction	14	6%
22	Referral	8	3%

Higher percentages of providers identified gaps in services than did consumers due to the fact that providers were asked to consider a service as a gap if a substantial number of their clients had trouble accessing a service, while each consumer vote represents the response of a single individual. As a result, provider-identified service gaps are useful as a measure of provider opinions about the Continuum of Care, rather than in determining the possible magnitude of service gaps for the population of PLWH in King County.

As in 1999, providers identified housing assistance and housing related services as the number one gap for the clients they served. In key informant interviews, providers pointed to long waiting lists for subsidized housing, limited options for PLWH with families and dependent children, rising rental costs and low vacancy rates as key barriers. Many providers noted that locating housing for their clients who are actively substance using and/or have criminal histories can be extremely difficult.

Providers also ranked substance use treatment and mental health counseling among the top service gaps for their HIV+ clients. This is consistent with provider reports that growing percentages of their caseloads are presenting with significant mental health issues (ranging from

situational depression to psychoses) and substance use histories (with increasing numbers of clients with multi-drug use). Although many providers noted that communication and collaboration between the HIV, mental health and substance use systems has improved in recent years, they also noted that many barriers still exist in helping their clients access these services. Among the most common barriers noted were client disinterest in using the services, denial that the service was necessary, and lack of insurance coverage and payment options.

It is also interesting to note that more providers reported gaps in helping their clients access abstinence-based substance use treatment programs than harm reduction programs. Twenty-nine percent of providers reported a gap in programs that help clients quit drug or alcohol use versus 17% who reported a gap in programs that help clients manage their use. It is unclear whether this points to improved access in recent years to harm reduction programs, or a feeling on the part of some providers that abstinence from substance use is the appropriate treatment modality for their clients.

Within the client advocacy category, the greatest gaps were reported in the areas of benefits counseling (other than by a case manager) (10%) and medical information about HIV/AIDS (9%). Seven percent of respondents identified gaps in accessing interpreter services, and 6% identified a gap in peer advocacy.

Comparison between 1999 and 2001 provider-identified service gaps: Very few significant changes emerged between provider-identified service gaps from 1999 to 2001 (Table 17). Based on input from key informant interviews, it appears that this is due to similar factors as those noted in consumer focus groups: ongoing gaps, such as in meeting needs for rental assistance and low income housing, in which Ryan White funds are incapable of fulfilling consumer need, and developing gaps among emerging consumer sub-populations, such as immigrants and persons without legal status.

Only two categories experienced significant increases from 1999 to 2001 in the percent of providers who identified them as gaps: client advocacy and ambulatory medical care. Client advocacy ranked as the 11th highest gap in 1999, with 12% of providers identifying lack of access to one or more of the sub-components of this category (benefits counseling other than by a case manager, medical information about HIV/AIDS, interpreter services and peer or client advocacy). In 2001, client advocacy rose to the number four gap, with 28% of providers identifying a service gap in this category for the clients. The bulk of this increase is related to the addition of non-case management benefits counseling and peer advocacy to the overall service list on the survey, neither of which were included on the 1999 survey.

**Table 17. Comparison Between 1999 and 2001
Provider-Identified Service Gaps**

Service	1999 % (N=224)	2001 % (N=253)
Adult day health	10%	12%

Alternative/non-Western therapies	15%	14%
Ambulatory/outpatient medical care	2%	10%
Case management	9%	11%
Child care	8%	6%
Client advocacy	12%	28%
Counseling (emotional support)	23%	25%
Dental care	22%	27%
Direct emergency financial assistance	22%	18%
Drug prescription programs (ADAP)	8%	13%
Food/meals	7%	10%
Home health care	11%	14%
Housing assistance/related services	46%	44%
Insurance programs	16%	17%
Legal assistance	13%	13%
Mental health therapy/counseling	32%	30%
Referral	3%	3%
Substance use treatment/counseling	26%	32%
Transportation	19%	23%
Volunteer home chore	4%	9%

NOTE: The categories of “Health Education/Risk Reduction” (reported as a gap by 6% of providers in 2001) and “Treatment Adherence Support” (reported by 21% of providers in 2001) were not included on the 1999 provider survey. As a result, cross-year comparisons are not possible.

In addition, the percent of providers who noted that medical information about HIV/AIDS was lacking for their clients rose from 3% in 1999 to 9% in 2001. Based on interviews with key informants, this gap is primarily due to the increase in clients whose primary language is neither English nor Spanish, and for whom written materials about HIV are less readily available.

Although the increase in the percent of providers who noted a gap in their clients’ access to primary care is significant, it remains relatively small (2% in 1999; 10% in 2001). Key informant interviews revealed that this gap is not actually due to lack of available slots for medical care. Rather, providers noted that the gap was seen as being related to increasing numbers of clients with mental illness and substance use histories (for whom these co-morbidities often serve as barriers to clients maintaining medical care) and the emerging population of refugee PLWH persons without legal standing. For these individuals, cultural norms against seeking medical care until one is very sick (or lack of trust in the Western medical system) was the key access barrier that prevented clients from obtaining the level of care their providers believed they needed.

Comparison between Consumer and Service Provider Gap Rankings: As in previous years, consumers and providers differed greatly in the service gaps they identified in the King County Continuum of Care. Significant differences emerged in the percentage of consumers and providers identifying gaps in almost two-thirds of the 22 Ryan White service categories, with providers being more likely than consumers to identify service gaps in all but two of those categories.

It is difficult to determine if this disparity represents actual differences in consumer versus provider perceptions of service gaps, or a methodological limitation (since consumers were asked to identify personal gaps while providers were asked to identify service gaps across the entire population of clients with whom they worked). Aggregate provider response may, in fact, overstate gaps by inflating gaps for small numbers of consumers into system-wide problems. Conversely, it is possible that provider responses were more reflective of actual gaps for populations that the consumer survey may have under-sampled: housing (homeless persons), mental health therapy (mentally ill persons), substance use treatment (chemically dependent persons) and transportation (PLWH living in non-urban parts of the county).

Similar to 1999, the largest disparities in consumer and provider-identified service gaps emerged in the areas of housing assistance, mental health counseling, and substance use treatment. Access to housing and housing-related services ranked first among provider-identified service gaps (44%), but ranked 5th as a consumer-identified gap (19%). Similarly wide disparities occurred in the areas of mental health counseling (identified as a gap by 30% of providers, but only by 10% of consumers) and substance use treatment (32% of providers, 4% of consumers). In addition, a significant gap emerged in 2001 between providers who identified transportation gaps for their clients (23%) versus consumers who noted this gap (3%).

Providers were also significantly more likely than consumers to identify gaps in the new category of treatment adherence support (21% versus 5%). Interestingly, of the 469 consumer survey respondents who reported taking at least one type of HIV-related medication (87% of total), 35% reported having difficulties taking the medications as prescribed. Thus, it appears that the majority of consumers who are experiencing treatment adherence problems do not believe that formal program support is lacking in assisting them with adherence.

H. Comparison of Service Priorities and Service Gaps

Consumer-identified service priorities as compared to service gaps: Comparing service gaps with service priorities helps determine the magnitude of potential system inadequacies and supports strategic planning and resource allocation decisions. Table 18 lists the top ten consumer-identified service priorities in comparison with the gap ranking and percentage for each service. Seven of the top ten consumer priorities also ranked among the top ten gaps.

Consistent with results from 1999, the services that consumers reported as having the highest priority-to-gap ratios were emergency financial assistance (31% of consumers rating the service

as a priority and 24% identifying it as a gap), alternative therapies (29% and 22%, respectively) and client advocacy services (35% and 20%, respectively).

Table 18. Service Priorities as Compared to Service Gaps from Consumer Surveys

Service	PRIORITY (n=511)		GAP (n=538)	
	Rank	% of Resp.	Rank	% of Resp.
Ambulatory/outpatient medical care	1	63%	21	1%
Dental care	2	56%	6	15%
Case management	3	50%	18	4%
Housing assistance/related services	4	47%	5	19%
Insurance programs	5	41%	13	6%
Drug prescription program (ADAP)	6	40%	17	5%
Client advocacy	7	35%	4	20%
Direct emergency financial	8	31%	1	24%
Alternative, non-Western therapies	9	29%	2	22%
Food/meals	10 (tie)	29%	9	10%
Mental health therapy/counseling	10 (tie)	29%	8	10%

Outpatient medical care and case management (identified among the top three service priorities across almost all sub-populations of PLWH) were rarely identified as gaps. Only 1% of consumers reported that they needed, but could not obtain outpatient medical care, and only 4% identified case management as a service gap.

I. Access Barriers

The survey asked all consumers who identified services as “need, but can’t get” to provide specific reasons why they could not access the service. Responses were coded by type of barrier identified. Table 19 includes cumulative responses of consumer-identified access barriers across all service categories.

Table 19. Access Barriers from Client Surveys (N=538)

Rank	Barrier	Number of Respondents	%
1	Lack of information	140	26%
2	Financial (can’t afford it)	97	18%
3	Not available/service doesn’t exist	38	7%
4	Eligibility (based on financial status)	36	7%

5	Quality of service is unsatisfactory	34	6%
6	Geography (live too far away)	30	6%
7	Waiting list; not enough services	27	5%
8	Conflicts with schedule or work hours	24	5%
9	Haven't asked yet	21	4%
10	Eligibility (based on disability status)	20	4%
11	Eligibility (non-specific)	15	3%
12	Client is uncomfortable/afraid to ask	10	2%
13	Entitlement amount is too low	9	2%
14	Agency is unresponsive to request	6	1%
15 (tie)	Request for service is in process	5	1%
15 (tie)	Language barriers	5	1%
17 (tie)	Lack of comfort at agency/provider	3	1%
17 (tie)	Too much bureaucracy/paperwork	3	1%
19 (tie)	Eligibility (based on citizenship status)	2	<1%
19 (tie)	Concerns about confidentiality	2	<1%
21 (tie)	Discrimination based on sex, race, etc.	1	<1%
21 (tie)	Criminal history/violent behavior	1	<1%

The two main barriers identified by consumers in accessing services were lack of information about available services (identified as a barrier by 26% of respondents) and inability to afford services (reported by 18% of respondents). No other barriers were identified by more than 7% of consumer respondents. These results are almost identical to barriers reported in both 1997 and 1999, although the percentage of consumers who identified financial barriers to accessing services has decreased from 25% in 1999 to 18% in 2001.

Unlike previous years, no significant differences emerged in identifying access barriers based on disease status. In prior years, persons who were HIV+ and symptomatic were more likely to experience barriers to accessing services than either HIV+ asymptomatic consumers or persons living with AIDS. The magnitude of the differences has decreased in the past four years. HIV+ asymptomatic consumers remain somewhat more likely than other PLWH to report a lack of information about available services and problems affording needed services, most likely due to needs-based service criteria in some service categories that prioritize disabled individuals over other potential service users.

It bears noting that in most service categories, many of the consumers who identified access gaps failed to identify specific barriers that contributed to their lack of access. As a result, “no

answer” accounted for between 20%-50% of access barrier response, depending on the service category. This is largely due to the nature of the open-ended response option. As a result, it is possible that the actual percent of consumers who have experienced one or more of the barriers mentioned is larger than is quoted on Table 19.

Access barriers by specific services: In most service categories, no pattern emerged regarding specific access barriers, with consumers reporting a mix of different barriers. These included financial and geographic barriers, lack of information and others. In many cases, survey respondents did not provide any reasons why they could not access a needed service. In some service categories, however, a clearer picture emerged regarding the association between a specific type of barrier and gaps in service delivery. The areas which were identified as largest service gaps associated with specific access barriers are:

- Alternative/non-Western therapies: Financial barriers to accessing care emerged as the most frequent reason why consumers felt that they could not access alternative therapies. Forty-five percent (44 out of 97) of survey respondents who identified a gap in naturopathy noted this barrier, as did 42% of those who could not access acupuncture or Chinese medicine (34 out of 81). Lack of information, the main access barrier associated with gaps in this service in 1999, was only mentioned by 29% of PLWH who could not access naturopathy and 17% of those who had difficulty accessing acupuncture. Although insurance coverage for these therapies has improved somewhat in recent years, most insurance policies do not cover alternative therapies, and higher income consumers may not be eligible for Ryan White-funded services.
- Client advocacy: Within the component services in this category, lack of information about where and how to access the service emerged as the primary access gap. This barrier was identified by 42% of consumers (23 out of 55) who identified a gap in peer or client advocacy, 46% of those who identified a gap in access to medical information (13 out of 28) and 38% who noted a gap in non-case management benefits counseling (22 out of 58).
- Counseling (emotional support): Thirty-nine percent of the consumers who identified a gap in one-to-one peer emotional support (29 out of 74) identified lack of information as the main barrier. However, conflicts with scheduling and work hours was noted as the main barrier for consumers who wanted to access support groups (listed as a barrier by 21% who identified this gap [13 out of 63]). Geographic barriers (living too far from the where the service is offered) prevented 16% (13 out of 63) of those who needed support groups from accessing this service.
- Dental care: One third of the respondents who noted a gap in dental care services stated that they could not afford the service (27 out of 81; 54%), primarily because their insurance did not cover the procedures they needed. This represents a decrease in the percent of consumers who noted they could not afford dental care in 1999.
- Direct emergency financial assistance: Consumers who were unable to obtain financial assistance most commonly reported that they were unsure about where to access these funds.

This barrier was identified by 24% of consumers who could not get help paying for groceries (20 out of 85) and 30% of consumers who could not get help paying utility bills (30 out of 100). Approximately 14% of consumers who could not access each of the sub-components of emergency financial assistance stated they were above the income eligibility criteria for the programs.

- Housing assistance and related services: Lack of information also emerged as the main gap identified by consumers who could find help accessing low income housing (25%; 17 out of 67) or help paying rent (28%; 21 out of 75). Eligibility based on financial status was listed as the second largest barrier, reported by 12% of consumers in need of low income housing and 16% of consumers in need of help paying rent. In 1999, 20% percent of the consumers who reported needing, but not being able to access housing, noted barriers related to long waiting lists and limited housing options. In 2001, this concern was only identified by 9% of consumers who noted a gap in finding low income housing (6 out of 67).
- Mental health therapy and counseling: Of the 56 consumers who identified a gap in accessing professional mental health services, affordability and lack of information emerged as the two biggest access barriers. Each was identified as a barrier by 29% of PLWH unable to access mental health services (16 out of 56).

J. Access Services

In response to the Health Resource Service Administration's increased focus on medical care access and engagement, the Planning Council added a new component to the 2001 consumer and provider surveys. The 2001 survey asked consumers and providers to identify the services they felt were most important in helping them or their clients access or maintain medical care ("access services"). Table 20 includes cumulative consumer responses.

**Table 20. Access Services from Consumer Surveys
(N=500; 38 missing/invalid responses)**

Rank	Service	Total Votes	%
1	Case management	290	58%
2	Insurance programs	238	48%
3	Dental care	228	46%
4	Client advocacy	216	43%
5 (tie)	Drug prescription program (ADAP)	202	40%
5 (tie)	Housing assistance/related services	202	40%
7	Counseling (emotional support)	148	30%
8	Mental health therapy/counseling	147	29%
9	Direct emergency financial assistance	130	26%
10	Alternative, non-Western therapies	127	25%
11	Food/meals	122	24%
12	Legal assistance	85	17%
13	Transportation	82	16%
14	Adult day health	61	12%
15	Referral	54	11%
16	Home health care	50	10%
17	Treatment adherence support	49	10%
18	Substance use treatment/counseling	43	9%
19	Volunteer home chore	33	7%
20	Health education/risk reduction	17	3%
21	Child care	13	3%

(NOTE: Because the purpose of this question was to inquire specifically about access to medical

care, the category of “primary medical care” was not included among the choices of access services in order to avoid redundancy. As a result, only 21 service categories are ranked, instead of the 22 noted in other sections of this report.)

In general, consumer rankings of access services were extremely similar to their rankings of service priorities. This may suggest that consumers believe the services that they feel are most important to them in living with HIV are also those that help them access and/or maintain medical care. However, several survey respondents noted in marginalia comments on the survey form that they were unclear about the distinction between “most important services” and “services that help you get or keep your medical care.” As a result, similarities between consumer-identified service priorities and access services may be due to design flaws in the survey itself.

Only five of 21 service categories demonstrated significant difference in the percent of consumers who identified them as access services versus service priorities. Case management, ranked as a priority service by 50% of consumers, emerged as the highest ranked access service. Fifty-eight percent of respondents stated that case management was important in helping them get or maintain medical care. Consumers also were significantly more likely to identify client advocacy and insurance programs as access services than as service priorities. Dental care and housing assistance were the only two service categories identified by significantly fewer consumers as access services than as service priorities.

Table 21 lists the rankings of access services as defined by providers. As with consumer-identified rankings, provider rankings of access services tended to be very similar to their rankings of service priorities.

Several services emerged among providers as significantly higher access services than service priorities. Chief among these was client advocacy. Fifty-seven percent of providers ranked client advocacy as a key access services, versus 39% of providers who identified client advocacy as a service priority. Each of the component parts of the category (medical information, benefits counseling, interpreter services and peer or client advocacy) were ranked as an access service by higher percentages of providers than as a service priority.

Insurance programs and transportation services were also significantly more likely to be identified by providers as services that helped consumers access or maintain their medical care. Thirty-three percent of providers listed transportation services as a key access service, up from 23% of providers who listed it as a service priority. Thirty-two percent of providers listed insurance programs as a key access service, up from 23% of providers who listed it as a service priority.

Several services were significantly less likely to be seen as key access services than as general service priorities by providers. These include drug prescription programs (listed as a service priority by 55% of providers, but as an access service by only 42%), dental care (22% versus 9%) and food/meals (12% versus 3%). It may be that providers did not consider drug prescription programs as a service that helped consumers access medical care because this service could be

viewed as an outcome of medical care itself.

**Table 21. Access Services from Provider Surveys
(N=245; 11 missing/invalid responses)**

Rank	Service	Total Votes	%
1	Case management	169	69%
2	Client advocacy	139	57%
3	Mental health therapy/counseling	137	56%
4	Substance use treatment/counseling	128	52%
5	Drug prescription programs (ADAP)	103	42%
6	Housing assistance/related services	88	36%
7	Transportation	82	33%
8	Insurance programs	79	32%
9	Treatment adherence support	74	30%
10	Counseling (emotional support)	67	27%
11	Adult day health	49	20%
12	Home health care	32	13%
13	Referral	31	13%
14 (tie)	Alternative, non-Western therapies	22	9%
14 (tie)	Dental care	22	9%
16	Legal assistance	15	6%
17	Direct emergency financial assistance	14	6%
18	Health education/risk reduction	11	4%
19 (tie)	Child care	8	3%
19 (tie)	Food/meals	8	3%
21	Volunteer home chore	7	3

K. Estimates of Unmet Need

Estimates of overall unmet service needs can prove very useful in making funding allocations and planning service delivery. In order to estimate how many consumers might have an unmet need in each of the services in the Continuum of Care, data from the consumer survey were compared to current epidemiological data. “Unmet need” data was drawn from consumer survey respondents who identified a service as “need, but can’t get.” Overall unmet need figures were derived by applying survey response percentages across estimates of King County male and female PLWH, controlling for known HIV status. Table 22 shows the estimated consumer need in each service category, and includes breakdowns by component services in collapsed categories (shown in italics).

Because survey sampling was devised in efforts to reach traditionally under-represented populations, need estimates were adjusted to better approximate the percentages of male and female PLWH and PLWA in King County. Survey response included purposeful over-sampling of women (14% of survey respondents versus an estimated 9% of PLWH) and persons who were living with AIDS (53% of survey respondents versus 33%-49% of all PLWH, depending on whether the high, low or midpoint estimated number of PLWH in the county is used). To derive more accurate estimates of need, the percentage of respondents in need within each service category was applied to the estimated number of male and female PLWH who were aware of their HIV+ status and male and female PLWA in the county. Gender and level of illness-specific figures were then added to develop an aggregate projection of need in each service category.

Service need estimates were calculated as follows:

1) Use of local epidemiological data: Asymptomatic HIV infection has only been reportable in Washington State since September 1999. Seroprevalence estimates for the county were taken from Public Health’s Epidemiology Program publication, HIV/AIDS Epidemiology Profile for Community Planning. Based on these data, the Epidemiology Program estimates that 6,000 - 9,000 persons in King County are believed to be infected with HIV, with 7,500 considered the midpoint value.

2) Breakdown of seroprevalence data into gender and level of illness: Public Health’s HIV/AIDS Epidemiology Program maintains current surveillance data regarding cumulative AIDS case counts and deaths in King County. As of 6/30/01, the number of persons presumed living with AIDS in the county was 2,643. If we assume that AIDS case reporting is approximately 90% complete, this would suggest a total of approximately 2,940 persons living with AIDS in King County. This includes approximately 2,725 males and 215 females.

The number of males living with AIDS in need of each of the various services was estimated by applying the percentage of male PLWA who stated they used or needed, but could not get, each service to the overall figure of male PLWA in the County. The same formula was used to derive the estimates for female PLWA in need.

3) Estimates of persons living with HIV (non-AIDS) in King County: The number of persons living with HIV (non-AIDS) in King County was derived by subtracting the estimated number of persons living with AIDS in the county from the total HIV+ estimate:

Low estimate:	$6,000 - 2,940 = 3,060$
Midpoint	$7,500 - 2,940 = 4,560$
High estimate	$9,000 - 2,940 = 6,060$

According to seroprevalence studies conducted in King County, the Epidemiology Program estimates that approximately 91% of the total number of persons living with HIV in King County are male and 9% are female. These percentages were multiplied across the total seroprevalence estimates for the County to derive the following numbers:

Males living with HIV (non-AIDS):

Low estimate:	$3,060 \times .91 = 2,785$
Midpoint	$4,560 \times .91 = 4,150$
High estimate	$6,060 \times .91 = 5,515$

Females living with HIV (non-AIDS):

Low estimate:	$3,060 \times .09 = 275$
Midpoint	$4,560 \times .09 = 410$
High estimate	$6,060 \times .09 = 545$

3) Estimate of HIV+ persons who are aware of their serostatus: Based on estimates from the Centers for Disease Control (CDC), approximately 75% of the estimated 900,000 HIV-positive persons in the United States know they are infected. Obviously, people who are living with HIV would not become consumers of HIV-related services until they are actually aware of their serostatus. In order to derive a more accurate estimate of consumers in need of services, it is therefore necessary to limit projections for HIV+, non-AIDS consumers to those individuals aware of their infection. As a result, the figures derived above for males and females living with HIV (non-AIDS) were multiplied by .75 to derive estimates of King County PLWH who are potential consumers of HIV-related services.

Males living with HIV (non-AIDS) who are aware of their serostatus:

Low estimate:	$2,785 \times .75 = 2,089$
Midpoint	$4,150 \times .75 = 3,113$
High estimate	$5,515 \times .75 = 4,136$

Females living with HIV (non-AIDS) who are aware of their serostatus:

Low estimate:	$275 \times .75 = 206$
Midpoint	$410 \times .75 = 308$
High estimate	$545 \times .75 = 409$

The number of males living with HIV (non-AIDS) in need of each of the various services was estimated by applying the percentage of males living with HIV (non-AIDS) who stated they used or needed, but could not get, each service to the low, midpoint and high estimates of males living

with HIV (non-AIDS) in the county. The same formula was used to derive the estimates for females living with HIV (non-AIDS) in need.

4) Calculation of percentage of consumers in need by service category: The need estimates for male PLWH, female PLWH, males living with AIDS and females living with AIDS were added to derive an overall estimate of consumer need in King County.

**Table 22. Estimates of Unmet Consumer Needs
by Service Category - King County**

Service Category	Unmet Need		
	Low Estimate ⁽¹⁾	Midpoint ⁽²⁾	High Estimate ⁽³⁾
Adult day health	239	292	346
Alternative/non-Western therapies	1,176	1,453	1,729
<i>Acupuncture/Chinese medicine</i>	785	957	1,128
<i>Naturopathy, herbal medicine</i>	942	1,148	1,355
Ambulatory medical care	47	69	91
Case management	205	262	319
Child care	48	53	59
Client advocacy	1,010	1,251	1,493
<i>Benefits counseling (other than CM)</i>	536	665	794
<i>Medical info about HIV/AIDS, tx., etc.</i>	274	354	435
<i>Interpreter services</i>	48	63	78
<i>Peer or client advocacy</i>	535	656	777
Counseling (emotional support)	1,063	1,293	1,523
<i>Support groups</i>	608	742	876
<i>One-on-one peer support</i>	740	912	1,083
<i>Spiritual and religious counseling</i>	361	450	538
Dental care	794	988	1,182
Direct emergency financial assistance	1,224	1,457	1,690
<i>Help paying utility bills</i>	943	1,142	1,342
<i>Help paying for groceries</i>	776	932	1,087

Table 22 (Continued)

Service Category	Consumers in Need		
	Low Estimate ⁽¹⁾	Midpoint ⁽²⁾	High Estimate ⁽³⁾
Drug prescription programs	243	305	367
Food/meals	472	593	714
<i>Home delivered meals</i>	<i>222</i>	<i>285</i>	<i>348</i>
<i>Food bank/receiving free groceries</i>	<i>296</i>	<i>368</i>	<i>440</i>
Health education/risk reduction	128	162	196
Home health care	251	290	328
<i>Home care worker (paid attendant)</i>	<i>148</i>	<i>172</i>	<i>195</i>
<i>Home nursing or infusion care</i>	<i>144</i>	<i>167</i>	<i>191</i>
<i>Skilled nursing facility</i>	<i>96</i>	<i>127</i>	<i>158</i>
Housing assistance	987	1,277	1,567
<i>Help finding low income housing</i>	<i>649</i>	<i>852</i>	<i>1,054</i>
<i>Help paying rent</i>	<i>723</i>	<i>921</i>	<i>1,118</i>
Insurance programs	312	404	496
Legal assistance	553	670	787
Mental health therapy/counseling	534	675	815
Referral	459	556	653
Substance use treatment/counseling	208	271	335
<i>Harm reduction</i>	<i>124</i>	<i>156</i>	<i>188</i>
<i>Help quitting drug/alcohol use</i>	<i>144</i>	<i>191</i>	<i>239</i>
Transportation	160	193	226
Treatment adherence support	245	303	362
Volunteer home chore	366	422	479

(1) Assuming 6,000 PLWH in King County

(2) Assuming 7,500 PLWH in King County

(3) Assuming 9,000 PLWH in King County

V. Specific Population Findings

Data on specific sub-populations of persons living with HIV/AIDS are drawn from several sources. Epidemiologic data and summaries are excerpted from HIV/AIDS Epidemiology Profile for Community Planning – June 2001, published by the HIV/AIDS Epidemiology Program of Public Health – Seattle & King County. All other information is derived from data from the 2001 consumer surveys, provider interviews, and focus groups. (See Section III, Methods) Quotes from persons living with HIV/AIDS have been excerpted from focus group transcripts and narrative sections of the consumer survey and are italicized in this report.

Within each sub-population, reports are organized as follows:

- 1. Epidemiologic Profile:** A summary of the population-specific data regarding AIDS case status and trends, population size, seroprevalence estimates and subgroup highlights (where appropriate).
- 2. Service Trends:** Patterns in overall service utilization, including demographic changes and population-specific needs as identified by consumers and providers.
- 3. Service Priorities:** Services that have been identified as priorities for the target population, by consumers themselves and/or by providers with expertise and experience in working with the population. The top ten priorities per sub-population from the consumer survey are listed.
- 4. Service Gaps:** Services that consumers and/or providers have identified as deficient, either because the service is not available, not accessible, or is not delivered in a manner consistent with sub-population needs. The top ten service gaps per sub-population from the consumer survey are listed.
- 5. Access Barriers:** Factors that have been identified by consumers and providers which impede service utilization by the population, including systemic barriers and population-specific attitudes and behaviors. The top five access barriers per sub-population from the consumer survey are listed. Suggestions for overcoming access barriers are also included.

(NOTE: All results noted as statistically significant were tested at the $p < .05$ level.)

A. Men who have Sex with Men

“Insurance keeps covering less, and a lot of meds for side effects are now over the counter. Co-pays which seem small add up too quickly when you have a chronic condition. I could get more assistance if I went onto disability. It seems to be an all-or-nothing approach that works against people who are struggling to work and only need partial assistance.” (White MSM PLWH)

1. Epidemiologic Profile

Men who have sex with men (MSM) were the earliest group affected by HIV/AIDS in King County and continue to bear the largest burden of AIDS, HIV infection, and risk of infection. Of persons living with AIDS in King County, 71% are MSM and an additional 10% are MSM who are also injection drug users (MSM/IDU).

Status and trends in AIDS cases: Although MSM are still the largest subgroup with AIDS in King County, AIDS case report data show a trend towards declining annual AIDS diagnoses in MSM beginning in 1994. The proportion of AIDS cases that are among MSM who do not inject drugs has decreased from 82% in 1982-85 to 62% in 1999-2000. The proportion of cases who are MSM drug injectors has remained at about 10% (varying from 7% to 12%).

Compared to AIDS cases, data on newly diagnosed HIV cases indicate an even lower proportion of MSM and a higher proportion of other exposure categories. Of 310 newly diagnosed HIV cases reported from 9/99 through 3/01, 61% were MSM, 8% were MSM/IDU and 31% had other or unknown risks.

Population sizes: Based on data from a variety of sources, Public Health – Seattle & King County estimates that MSM number between 32,000 and 53,000 in King County, including approximately 2,500-3,800 MSM drug injectors. HIV seropositive MSM are estimated to number 4,800-7,200, including 600-900 HIV-infected MSM drug injectors.

HIV seroprevalence: Depending on the site or population of MSM and the year of the survey, local HIV seroprevalence studies indicate that between 2.5% and 36% of MSM test HIV positive. Unlinked, anonymous HIV surveys conducted during 1998-99 at Harborview’s STD Clinic revealed that 8.6% of 488 MSM tested HIV+ positive. In the same STD Clinic survey, trend analysis showed that HIV prevalence decreased from 36% for all MSM in 1988-89 to 5% in 1996-97, but rose again to 11% in 1999. The increase observed in 1999 is statistically significant and may be a reflection of a possible upsurge in HIV transmission.

Subgroup highlights:

MSM of color: Most men of color currently living with AIDS reported male-male sex with or without IDU as a risk factor for HIV (69%). However, this proportion is lower than among white men living with AIDS (92% reporting male-male sex). In general, persons of color have a higher prevalence of HIV and AIDS than whites, but this is not necessarily the case for MSM.

MSM Injection Drug Users (MSM/IDU): Amphetamine use was reported by 40% of MSM drug injectors, in comparison to 4% of non-MSM drug injectors in unlinked seroprevalence studies at King County drug treatment centers from 1988 through 1997. In this study, the seroprevalence of HIV was 47% in MSM whose usual injection drug was methamphetamine, compared to 14% of MSM who primarily injected other drugs.

2. Service Trends

As in previous years, providers of services to MSM report that the large majority of their clients are white (ranging from 80%-90%, depending on the provider). Providers reported a slight increase in gay men of color, mostly among Hispanic MSM. Providers also noted that they are seeing younger MSM clients, especially those in their 20's. They are also seeing an increase in newly-diagnosed MSM clients over the age of 40, and more clients ages 50 and older as increasing numbers of PLWH are living longer due to HAART therapy.

Increasing numbers of MSM clients are living in South and East King County, as well as clients who travel to Seattle for care from across the state. Although a higher percentage of non-Seattle respondents on the consumer survey are non-MSM, the percent of consumers with zip codes outside Seattle who reported MSM activity has increased since 1999. Providers also reported a slight increase in homeless and formerly homeless MSM clients since the last assessment was completed in 1999.

As first identified in 1997, providers continue to see increasing numbers of MSM clients presenting with histories of mental illness and chemical dependency. In particular, providers noted a high incidence of depression in their MSM clients. In many of these cases, providers identified situational depression among the growing number of clients who thought that they were dying and are now living longer than anticipated. Providers also noted that more clients are presenting with anger management issues that impact the clients' ability to interact appropriately with providers. A increasing percentage of MSM PLWH are presenting with more severe mental health diagnoses which impact their daily living, such as psychoses and personality disorders. Thirty-one percent of overall MSM respondents to the consumer survey reported having been diagnosed with a mental illness, higher than the 26% of non-MSM PLWH survey respondents who reported having been diagnosed with mental illness.

Providers report that a growing percent of their MSM clients are current or former substance users. The "drug of choice" for many of these men is crystal methamphetamine, particularly among white MSM. Smaller numbers are also reported to be using cocaine. Use of alcohol and recreational drugs, such as stimulants and non-medical marijuana, is reported as being widespread. Providers whose caseload is primarily composed of MSM/IDU report an increase in multi-drug use among their clients.

Consistent with provider reports, white MSM respondents on the 2001 consumer survey are more likely to self-report as having been diagnosed with mental illness than MSM of color populations (33% versus 26%). White MSM are also more than three times less likely to have been homeless during the previous year (6% of white MSM versus 20% of MSM of color) and almost half as likely to have been in jail or prison (5% versus 9%).

MSM survey respondents reported several significant differences in disease status and progression than was reported among other PLWH. MSM were more likely than other consumers to have received an AIDS diagnosis (56% versus 46%). MSM were significantly more likely than other consumers to know their T-cell counts (92% versus 76%) as well as their viral loads (91% versus 71%). Among consumers who were aware of these respective health markers, MSM were more likely than other consumer to report T-cell counts under 200 (33% versus 25%) and viral loads over 10,000 (22% versus 12%).

A potential explanation for the difference in health status may be the disparity between MSM PLWH and others in terms of medication status. MSM consumers were significantly more likely than other survey respondents to be currently taking antiviral medications (83% versus 61%), protease inhibitors (57% versus 39%) and drugs to treat or prevent opportunistic infections (45% versus 35%). This difference applies to both white MSM and MSM of color, both of which are more likely than non-MSM to be taking HIV-related medications.

Providers of services to MSM noted that access to needed HIV medications was rarely an issue for their clients. Medical providers noted that compliance with complex dosaging regimens continues to be a problem for significant numbers of their patients. Several providers reported that their patients are taking “drug holidays.” In many cases, providers noted that non-compliance on the part of their clients has led them to suspend or end treatment regimens. Providers also stated that a growing percent of their MSM patients are experiencing debilitating side effects from HAART therapy, also leading physicians and clients to alter or terminate these regimens.

“I am afraid that if anything changes, my health will go downhill like the Titanic. I have struggled with the beast, and can only be grateful I am doing this well. Sometimes I wish I would die because I have depression and episodes.” (White MSM PLWH)

Providers noted that they are seeing increased morbidity among their long-term clients. The types of illness with which clients are presenting include heart disease, STD’s, liver disease, bacterial pneumonia and an increase in lymphomas. Clients also appear to be experiencing more dental problems related to long-term survival with HIV. In 1999, very few providers reported deaths among their clients during the year. In recent months, however, providers have noticed a steady increase in client deaths, particularly among long-term clients and among those who have failed repeatedly on HAART therapies.

The percent of MSM who are not in care appears to be very small, and has continued to decline in recent years. MSM of color were equally likely as white MSM to be using primary medical care (96% and 95%, respectively). Only 4% of MSM survey respondents reported not currently using outpatient medical care, with less than 1% stating that they could not access the service. The others stated either that they felt they did not need medical care, or preferred to receive primary care from a non-Western practitioner.

White MSM survey respondents reported high utilization of other clinical and support services as well. However, unlike in previous survey years, white MSM exhibited service utilization rates that were lower than MSM of color in most service categories. Of particular note is that white

MSM were less likely than MSM of color to report utilization of the Washington State ADAP program (50% versus 64%), food and meal programs (43% versus 57%), housing services (41% versus 51%) and transportation programs (27% versus 35%).

White MSM were also less likely than MSM of color to use HIV-related case management (79% versus 89%). White MSM in focus groups noted frustration with recent high turnover rates in local case management programs, but noted that they felt this had required them to become better self-advocates for services. Eighty-two percent of white MSM reported using one or more of the component services of client advocacy, with greatest utilization being medical information about HIV/AIDS.

MSM of color: As in previous years, the majority of MSM of color live in Central and South Central Seattle and in South King County. Homelessness has also increased in this population. Providers report that their MSM of color clients are generally of lower income levels than white MSM and are less likely to have private insurance coverage.

Providers also noted that their clients who are MSM of color were generally less likely than white MSM to openly identify as gay/bisexual in their communities, and were less likely to be involved in the gay community at-large. This is particularly true of Latino MSM (especially those who are non-English speaking) and American Indian/Alaska Native MSM (especially those who were raised in non-urban and/or reservation settings). This dual isolation decreases the chances that information about HIV/AIDS services is reaching MSM of color. Providers reported seeing increasing numbers of MSM without legal standing, including MSM immigrants and refugees from African and Latin American countries.

Survey results suggest that MSM of color are significantly more likely than white MSM to report themselves as being HIV+ and asymptomatic (40% versus 27%). Consistent with 1999 needs assessment results, MSM of color were significantly more likely than white MSM to be unaware of their T-cell counts (15% versus 5%) and viral load levels (19% versus 7%). Similar to white MSM, lack of access to outpatient medical care was not reported by MSM of color, either in surveys or in focus groups. However, providers of services to persons of color stated that education and information gaps about HIV issues may exist for their clients of color. In addition, immigrant MSM of color may also exhibit gaps in their understanding of the medical system in general. For some members of these populations, there may be a lack of trust in Western medical care or a cultural norm against seeking medical care unless debilitating clinical illness exists.

As with white MSM, access to prescription drugs did not emerge as a significant problem, but providers noted that medication compliance can be complicated by language barriers, cultural norms about taking medications and lack of trust in Western medicine. Even more so than with white MSM, providers of services to MSM of color report that many of the clients are unwilling to continue their medication regimens until adverse side effects can be negated. Nevertheless, 77% of MSM of color reported taking antiviral medications and 54% reported taking protease inhibitors. Thirty-four percent of MSM of color report having problems adhering to their medical regimens. These figures are lower than those reported by white MSM, but not statistically significant.

MSM of color were somewhat less likely than white MSM to report being diagnosed with mental illness (26% versus 33%). However, providers reported that they are seeing increases in the percent of their MSM of color clients who are presenting with depression and dementia. MSM of color were slightly more likely than white MSM to report having injected drugs in the past year (10% versus 8%). Homelessness appears to be a significantly greater problem among MSM of color than white MSM, with 20% of MSM of color survey respondents stating that they had been homeless in the past year versus 6% of white MSM.

MSM of color survey respondents reported somewhat higher utilization rates than white MSM of most other clinical and support services. Fifty-seven percent of MSM of color reported using peer support counseling, and 57% reported using food and meal programs. Utilization of client advocacy services was particularly high, with 88% of MSM of color reporting using one or more of the component services in this category, with greatest utilization being medical information about HIV/AIDS (for African American MSM) and legal assistance, such as help with immigration issues (for Latinos). Unlike previous years, the percent of MSM of color using dental care is now equal to the percent of white MSM using the service (both at 73%).

MSM/IDU: Providers of services to MSM drug injectors reported similar client demographics as non-injecting MSM, with the majority of clients being in their 30's. Almost all of the MSM/IDU clients currently being seen have incomes below poverty level. Providers described several of their clients as being "precariously employed."

Providers noted that about half of their MSM/IDU clients have had histories of incarceration, with many still actively involved with the court system. Consumer survey data supports this observation, with MSM/IDU survey respondents significantly more likely than non-IDU MSM to report having been in jail or prison in the past year (22% versus 4%). MSM/IDU respondents were also significantly more likely than other MSM to have been homeless in the past year (24% versus 7%).

MSM/IDU were also significantly more likely than other MSM to report having been diagnosed with a mental illness (57% versus 27%). Providers noted that they are seeing very high rates of depression among their MSM/IDU clients. This is particularly true for crystal meth users, who frequently present with attention deficit disorder, impacting their ability to maintain healthy lifestyles and adhere to treatment regimens.

"Sometimes I want to go and loudly tell everyone what I have, but I really can't. There's too much stigma and fear out there. So I just told my family members, miles away from where I live. My children give me strength, along with the enigmatic future that sits in front of them and me." (White MSM/IDU PLWH)

As first reported in 1997, providers noted that MSM/IDU clients who are responding well to protease inhibitors are healthier, while those who have not responded to the new medications are becoming sicker more rapidly. Providers noted that clients who are experiencing declines in their general health are less likely to be engaged in substance use treatment. Although providers noted a slight increase in HIV-related morbidity and mortality in this population, they noted that it was unclear if this trend was related to HIV or substance use. Providers also stated that their

clients are more knowledgeable about their own health status than in past years, and that they are more engaged in health care. MSM/IDU consumer survey respondents reported health status indicators which were statistically similar to the population of non-IDU MSM, with no major differences reported in level of HIV disease, T-cell count or viral load.

As with other populations, providers reported that their MSM/IDU clients had not experienced difficulty in accessing HIV medications, although adherence to medication regimens was problematic. Providers stated that adherence is generally reflective of the client's substance use pattern. Those who are having problems managing their substance use are most likely to have problems managing their HIV medication regimens. However, substance use counselors noted that they are seeing some improvement in the ways in which medical providers are working with their substance-using clients. In many cases, they noted, this means that doctors have begun to incorporate "harm reduction" modalities into their treatment styles. As a result, MSM/IDU survey respondents reported medication usage rates that were almost identical to other MSM.

3. Service Priorities

MSM survey respondents ranked primary medical care as their highest service priority, followed by dental care, case management, housing assistance and insurance programs (Table 23).

Unlike in 1999, significant differences emerged in several categories between the ways in which MSM and non-MSM prioritized services. MSM were significantly more likely than non-MSM to prioritize clinical services, such as primary medical care (67% of MSM versus 49% of non-MSM), dental care (59% versus 45%), and mental health therapy and counseling (31% versus 18%). Conversely, MSM were less likely to prioritize support services such as emergency financial assistance (28% versus 39%), food and meal programs (25% versus 36%), housing assistance (44% versus 60%) and client advocacy (33% versus 43%).

Table 23. Service Priorities : MSM (n=410; 21 missing responses)

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Ambulatory/outpatient medical care	274	67%
2	Dental care	241	59%
3	Case management	208	51%
4	Housing assistance/related services	181	44%
5	Insurance programs	172	42%
6	Drug prescription program (ADAP)	168	41%
7	Client advocacy	137	33%
8	Mental health therapy/counseling	126	31%
9	Alternative, non-Western therapies	124	30%
10	Direct emergency financial assistance	115	28%

Participants in the MSM focus group exhibited a high level of knowledge about the medical care system and HIV-related medical issues. They demonstrated strong self-advocacy skills in

general and expressed more confidence in their abilities to navigate the Continuum of Care than did other populations.

MSM of color: MSM of color ranked services in a fairly similar manner to white MSM, although the percentage of consumers in each population showed some differences. The top five service priorities for MSM of color were case management, dental care, housing assistance, primary medical care and insurance programs. Services prioritized by significantly higher percentages of MSM of color versus white MSM included housing assistance (57% versus 40%), client advocacy (46% versus 30%) and treatment adherence support (11% versus 4%). MSM of color were significantly less likely than white MSM to prioritize primary medical care (56% versus 70%).

MSM/IDU: Several significant differences emerged on the consumer survey in the ways in which MSM/IDU and non-IDU MSM prioritized services. Housing assistance and related services emerged as the top service priority for MSM/IDU, followed by case management, primary medical care, drug prescription programs, food/meal programs and dental care.

MSM/IDU were significantly more likely than other MSM to prioritize housing services (61% versus 41%). Based on input from focus group participants and providers, housing for persons with substance use histories presents major challenges. Although many of the MSM/IDU participants are now living in the Lyon Building (a 64-unit residence, primarily serving HIV+ client with substance use and/or mental health histories) many expressed concerns about their ability to remain clean and sober when living amid the persistent drug activity in the downtown environment.

Not surprisingly, MSM/IDU were significantly more likely than other MSM to prioritize substance use treatment (25% versus 7%). They were also more likely to prioritize adult day health programs (23% versus 9%), which may be as much a function of survey sampling as of actual priorities. MSM/IDU were significantly less likely than other MSM to prioritize dental care (36% versus 60%) and insurance programs (16% versus 44%).

4. Service Gaps

MSM PLWH identified gaps in alternative/non-Western therapies more than in other categories. Other highly ranked service gaps for this population include emergency financial assistance, counseling (peer support), client advocacy and housing assistance. (Table 24) Within the counseling (peer support) category, the highest gaps emerged in one-one peer support (14%) and support groups (11%); in client advocacy, the highest gaps emerged in peer advocacy (10%) and benefits counseling (10%); and in housing, the highest gaps were in help paying rent (14%) and help in finding low income housing (12%).

MSM were no more or less likely than other PLWH to identify gaps for almost all service categories. In only two categories did significant differences appear: MSM were less likely than other PLWH to identify gaps in emergency financial assistance (22% versus 34%) and food and meal programs (8% versus 18%).

Table 24. Service Gaps: MSM (n=431)

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Alternative/non-Western therapies	99	23%
2	Direct emergency financial assistance	93	22%
3	Counseling (emotional support)	85	20%
4	Client advocacy	81	19%
5	Housing assistance/related services	76	18%
6	Dental care	63	15%
7	Legal assistance	46	11%
8	Mental health therapy/counseling	43	10%
9	Referral	39	9%
10	Food meals	33	8%

Although alternative therapies were identified as the top service gap, the large majority of MSM survey respondents who use alternative therapies are also currently using Western medical care. Complimentary therapies, such as acupuncture and naturopathy, are most commonly employed to lessen the pain of opportunistic infections and/or the side effects of HIV medications. The greatest gap exists for those consumers who cannot afford to pay for these treatments themselves, whose insurance does not cover alternative care, and/or who do not qualify for Ryan White-funded services.

“Working full time to make ends meet is very hard for those of us living with HIV. It is very hard to get assistance when one makes too much money. Too many agencies make you feel unwelcome and make you jump through too many hoops. You have to give up your quality of life to get an assistance.” (White MSM PLWH)

Providers noted that they are seeing MSM clients in general who are seeking more help with financial assistance and insurance income benefits. Growing numbers of MSM clients are entering the system with no income and/or no insurance. Many clients are interested in re-training problems to assist them in getting back to work, but concerns exist about their ability to maintain ongoing employment and the potentially adverse effects employment may have on their benefits.

Providers reported service gaps for their MSM clients (and clients in general) in accessing Medicaid dental care due to a severe shortage of providers who are willing to accept this form of payment. Additionally, providers noted that coverage for complex procedures such as bridges, crowns and dentures is relatively impossible to secure for their clients. Consumers expressed frustration in navigating the dental care system, reporting extensive delays in accessing even basic dental care. Based on reports from providers, emergency dental appointments are also hard to secure.

MSM of color: MSM of color identified the same services as their five greatest service gaps as white MSM, although the rank order was different. The top five service gaps for MSM of color

were housing assistance, counseling (peer support), emergency financial assistance, alternative therapies and client advocacy.

In general, MSM of color were more likely than white MSM to report gaps in the provision of services. In several cases, these differences reached statistical significance. MSM of color were almost twice as likely as white MSM to identify gaps in housing services (29% versus 15%), particularly in help finding low income housing. Other key differences emerged in the areas of peer counseling (27% versus 17%), legal assistance (18% versus 8%), and adult day health (15% versus 2%). Within the category of peer counseling, the largest gap emerged in one-on-one peer support (24% versus 11%), with particularly large gaps noted by Latino MSM.

“My wish is for some type of activity or work for Latinos living with HIV/AIDS, even if the pay was low. At least we could keep ourselves occupied. For example, even manual labor where we could establish our citizenship or something that could serve as a distraction.”
(Latino MSM PLWH)

Providers of services to MSM of color concurred with their clients’ assessment, noting greater service gaps than did providers of services to predominantly white MSM clientele. In addition to the services mentioned above, providers identified gaps in low income housing (particularly for undocumented PLWH) and transportation services (particularly for persons living in East and South King County).

MSM/IDU: Drug injecting MSM identified several different service gaps than non-injecting MSM. The three largest gaps reported by MSM/IDU were in the areas of mental health therapy, counseling (peer emotional support) and housing assistance, none of which ranked among the top three gaps for non-IDU MSM. MSM/IDU were more than three times as likely as non-injectors to identify gaps in substance use treatment and counseling (25% versus 7%) and over twice as likely to identify gaps in adult day health programs (23% versus 9%). MSM/IDU PLWH were also significantly more likely to identify gaps in housing assistance (61% versus 41%).

Providers of services to MSM/IDU PLWH echoed these sentiments. They noted that abstinence-based housing criteria are often impossible for their clients to adhere to. As a result, clients who are in gradual recovery (particularly those who have entered harm reduction programs) may lose what few housing options are available to them. Providers also noted that their clients may have problems accessing adult day health programs if they are not medically sick enough to meet eligibility criteria or if their substance use keeps them from participating on a regular basis.

5. Access Barriers

Prior to 1999, MSM survey respondents were less likely than other populations (such as women and injection drug users) to identify barriers to accessing care services. In recent years this trend seems to have ended. Similar percentages of MSM PLWH identified access barriers as other populations, with no statistically significant differences emerging.

Consistent with other populations, MSM consumers identified a lack of information about available services as their main access barrier (Table 25). This is especially true for MSM who

are geographically and socially isolated from the gay/bisexual male community in central Seattle. In particular, lack of information about where and how to obtain services was identified as the major barrier that prevented MSM PLWH from accessing alternative therapies and emergency financial assistance.

Table 25. Access Barriers: MSM (n=431)

BARRIER	# OF VOTES	% OF RESP.
Lack of information	111	26%
Financial (can't afford it)	82	19%
Eligibility (based on disability status)	34	8%
Eligibility (general)	33	8%
Quality of services is unsatisfactory	26	6%

Approximately one-fifth of MSM respondents identified access barriers related to financial constraints. For MSM whose income falls above 200% of FPL (the cutoff point for eligibility for Ryan White-funded services in the EMA), accessing services for which insurance coverage is less than optimal may be difficult. This includes mental health therapy, dental care and alternative/non-Western therapies.

As in 1999, MSM focus group participants expressed concern about staff turnover among case managers. The majority of participants had had more than one case manager during their illness, with several reporting having had three or four in a two-year period. They found this lack of continuity to be emotionally draining, particularly as they had to re-establish trust and build rapport with each new case manager. Several MSM in their 40's noted that succeeding generations of case managers appeared to be younger and younger, and that it was hard for them to feel confident in the abilities of staff whom they felt lacked experience in the HIV field.

Most providers felt that services were generally available to those clients who sought them or who followed through on referrals made by their medical providers or case managers. As in previous years, providers of services to MSM reported that access barriers for their clients were less dependent on sexual orientation than on issues of class, geography, race, and socioeconomic status. However, for MSM who are not "out" about their sexual orientation, accessing services may be limited by fear of disclosure and/or discomfort in perceived gay-identified environments.

As more clients are living longer with HIV, several of the most well-known HIV specialists in King County have closed their practices to new clients. Other providers are curtailing the number of new Medicaid patients they accept, due to low reimbursement rates. While access to primary care is not a widespread problem for PLWH in King County, new clients are finding that their preferred provider may be no longer available and that they may have to receive care from a provider who is potentially less established in the HIV field.

Mental illness is often another factor that limits access for clients. Providers noted that anger management issues are becoming increasingly common in their clients. This may serve as a

barrier to effective self-advocacy and lead to inappropriate interactions with providers and possible dismissal from services.

MSM of color: Two significant differences emerged in access barriers identified by MSM of color and white MSM. MSM of color were significantly more likely than white MSM to report being unable to access services due to lack of information (33% versus 23%), but less than half as likely to be unable to access services due to financial reasons (8% versus 23%).

“Due to the side effects of the medications, I am waiting as long as I can before I start taking them. I am trying to find as much information as I can, to be prepared. I feel my friends are my support group, but I learn most of my information from my friends on medications and from treatment presentations.” (African-American MSM PLWH)

As in previous years, focus group participants who were MSM of color stated that they often found themselves at a disadvantage in regards to knowledge of medical treatments and available services. This issue has lessened somewhat due to the emergence of new peer support and outreach programs for MSM of color, but an informational gap still exists for clients who are not yet familiar with the system. Financial barriers seem to be less of an issue for MSM of color than for white MSM due to the fact that a higher percentage of MSM of color seem to be eligible for Ryan White-funded services (77% of MSM of color report personal incomes under 200% of FPL versus 64% of white MSM).

Providers of services to MSM of color suggested that language barriers can serve as an obstacle for non-English speaking PLWH, such as immigrant Latinos and Asian/Pacific Islanders. Providers noted that their clients may feel culturally disenfranchised by both the mainstream gay white community and their communities of origin, which might disapprove of their sexuality. Finding peer social support can be extremely difficult under these circumstances.

MSM/IDU: No significant differences emerged in access barriers identified by MSM/IDU and non-injecting MSM. MSM/IDU were somewhat less likely than non-IDU MSM to identify barriers based on lack of information, perhaps because the MSM/IDU may have access to service information from both their HIV and substance use case managers.

Providers of services to MSM/IDU reported that substance use itself serves as the biggest barrier to accessing services for their clients. This also extends to clients' perceptions that they are being treated unfairly by providers in general. Clients who are active substance users may feel like they are being judged negatively by medical, mental health and social service providers and are denied access to medications and support services. If drug injecting clients perceive that they are stigmatized in this manner, they often will not access services or will not be honest about their substance use to providers.

Providers suggested the following recommendations about how to improve service delivery and client access for MSM living with HIV/AIDS:

- Advocate for more funding and identify alternative or previously-untapped funding streams. Providers felt that, as funding becomes tighter, a higher percent of funds is reserved for non-

MSM clients. As a result, their clients may feel that fewer services are available to them and that waiting lists for the services they desire are becoming more common.

- Improve access to dental care. Identify dental providers who are willing to accept Medicaid as well as those who can perform reduced-fee specialty care.
- Continue to educate all HIV providers about harm reduction strategies. Incorporate harm reduction into other program models, so that persons who are actively using and managing their use are not denied services.
- Increase adult day health slots for MSM/IDU, either within the existing program or at another agency.
- Develop more programs for MSM/IDU who are not primarily crystal meth users, including expanding programs for persons who are alcohol addicted.
- Expand housing options for non-AIDS disabled individuals. This includes developing more linkages between the AIDS housing field and housing opportunities in the mental health and substance use arenas.

B. Injection Drug Users

“I don’t do drugs any more, but when I did all the places required me to quit first and then they would help me. Come on! What’s up with that? My opinion is that if a person is on drugs, help them. If you treat the mental problem, the person would stop drugs on their own. I did.” (Homeless IDU PLWH, formerly incarcerated)

1. Epidemiologic Profile

As in other parts of the Western United States, the number of cases of HIV and AIDS among drug injectors in King County is far less than those among gay and bisexual men. However, the percent of cases attributable to injection drug use (IDU) in King County is on the rise. While the proportion of cumulative AIDS cases that were acquired via drug injection is 6%, in recent years nearly 10% of case have been attributed to IDU risk.

Status and trends in AIDS cases: There are an estimated 150,000 people in King County at increased risk of HIV infection because of illicit drug use or alcohol abuse. About 15,000 of these are at increased risk due to drug injection. The estimated number of HIV+ heterosexual IDU in King County is 400 to 650 (midpoint=525). The estimated number of men who have sex with men and also inject drugs is 600 to 900 (midpoint=750).

AIDS in female and heterosexual male IDU was first reported in King County in 1986. By the end of 2000, 346 cases had been diagnosed and reported in this group, representing about 6% of all King County AIDS cases. An additional 100 IDU had been reported with HIV infection, but had not developed AIDS.

The proportion of cases attributed to drug injection among heterosexuals has increased from about 3% of cases in 1983-1988 to 6% in 1992-1994, and 10% in 1998-2000. While the number of male IDU in King County reported with AIDS is higher than the number of female IDU, the proportion of male AIDS cases whose infection was attributed to IDU is 4% compared to 31% among females.

Injection drug use is a relatively more important route of HIV transmission for King County African Americans with AIDS (14% of cases), and Native American/Alaska Natives (21%) and Latinos/Latinas (10%) compared to whites (4%) or Asian/Pacific Islanders (3%).

HIV seroprevalence: In unlinked surveys conducted by Public Health – Seattle & King County of more than 7,000 drug users entering King County drug treatment programs between 1988-1999, 1.5% tested HIV positive. HIV prevalence among clients entering drug treatment in King County has hovered around 2% and has not changed significantly over the 12 years that these unlinked HIV surveys have been conducted.

2. Service Trends

According to information from providers of services to injection drug using PLWH, the overall demographics of the population have changed relatively little in the past two years. The population of IDU PLWH is still primarily male (approximately 60% of clients served), with

continuing increases in the number of HIV+ female IDU being seen. Approximately half of the male clients are white, with the rest almost equally divided between African-Americans and Latinos. Providers noted that their female IDU PLWH caseloads tend to be fairly diverse, including quite a few Native Americans and African Americans. Providers noted that most of their clients are in the 35-45 age range, with increasing numbers of younger clients (under the age of 25) using services in the past two years. IDU respondents to the consumer survey demonstrated almost equal sex and race demographics as non-IDU's, with 82% of IDU being male (versus 85% of non-IDU) and 72% identifying as white (versus 71% of non-IDU).

As in previous years, providers reported that almost all of their clients are living at or below the poverty level. Very few have legitimate jobs, although some sell drugs to support their addiction. IDU PLWH were significantly more likely than non-IDU survey respondents to report incomes below 100% of Federal Poverty Guidelines (49% versus 38%). Homelessness is also a major, and growing, problem in this population. Survey respondents with substance use histories were almost four times as likely as non-IDU PLWH to have been homeless in the past year (31% versus 8%).

Providers noted that well over half of their IDU clients have been in jail or prison, mostly for drug-related offenses. In many cases, incarceration is chronic, with clients returning to jail for repeat offenses. Providers also noted that the increased presence of law enforcement in downtown Seattle has increased the likelihood that their clients will become involved in the criminal justice system. Consumer survey data support this statement, as IDU PLWH were significantly more likely than other consumers to have been incarcerated in the past year (26% versus 4%).

As noted in previous years, providers are seeing increasing multi-drug use among their IDU clients, including rising rates of alcohol abuse. Methamphetamine use continues to increase, particularly among male IDU. Use of crack cocaine is more prevalent among female IDU. Heroin injection is frequently reported for both male and female IDU. Providers also noted that male IDU who have been in methadone treatment for heroin use may relapse into crack use.

Harm reduction programs continue to work well for many of the IDU PLWH who have accepted this approach, with providers reporting that these clients are using more safely, participating in needle exchange programs and entering and remaining in treatment in greater numbers and for longer periods of time than in past years. Conversely, providers also noted that they are seeing an increase in the number of clients who are sharing needles and engaging in unprotected sex.

“Drug users aren’t getting care because they’re still using. They’re not responsible. I probably know fifteen people that are HIV+ who are not getting care. You need to develop a clinic, give them their hit of heroin and then provide medical care, like that experimental clinic in London. “ (Female IDU PLWH)

Providers continue to report seeing increasing percentages of their IDU PLWH clients who are both chemically dependent and mentally ill. IDU survey respondents were significantly more likely than other PLWH to report having been diagnosed with a mental illness (52% versus 27%). The percent of IDU survey respondents who reported mental illness increased by 11% in

the past two years. Many of these clients are chronically mentally ill, with high levels of depression, bipolar disorder and cocaine-related psychosis.

Data from the 2001 consumer survey reveal several differences between HIV-related health care status between IDU PLWH and non-IDU PLWH. Although IDU were equally as likely as other consumers to be diagnosed with AIDS (as opposed to being HIV+, non-AIDS), IDU consumers were significantly more likely to have had their AIDS diagnosis based on low T-cell counts, rather than opportunistic infections. No significant differences emerged between IDU and non-IDU PLWH regarding the types of HIV-related medications they were taking, but IDU were significantly more likely to report having problems with HAART adherence (38% versus 29%). Although providers reported no actual difficulties for their IDU clients in accessing prescription medications, they did note that clients might perceive that medical providers will not put them on HAART therapy because of their substance use. Some clients may feel compelled to hide their substance use histories from their medical providers for this reason.

Providers reported increasing HIV-related morbidity among their IDU clients. In particular, female IDU are experiencing more hospitalizations and opportunistic infections, especially if they are homeless. Cervical and gynecological problems are also increasing in this population. In many cases, IDU PLWH discover their HIV status after being admitted to the hospital with life-threatening illnesses. Several participants in the IDU focus group reported learning about their HIV status in detoxification facilities, in prison or upon being hospitalized.

Based on responses to the 2001 consumer survey, service utilization by drug injecting PLWH was similar in most categories to that exhibited by other populations. Ninety-seven percent of IDU PLWH reported current utilization of primary care, and 50% reported using the State's AIDS Drug Assistance Program.

Both providers of services to IDU and IDU consumers themselves acknowledged the importance of case management in helping drug-injecting PLWH negotiate the care service system. IDU PLWH were more likely than other populations to use case management services (87% versus 77%). Drug injecting PLWH are also more likely than other consumers to be using food and meal services (60% versus 46%), and housing assistance (62% versus 42%). In both cases, these figures represent significant increases in utilization from the 1999 consumer survey. IDU survey respondents were less likely, however, to use client advocacy (71% versus 85%) and insurance continuation programs (39% versus 60%).

The number and percent of IDU PLWH who are utilizing substance use treatment services has also risen during the past two years. In 1999, 32% of IDU survey respondents reported using substance use counseling services. In 2001, this figure rose to 42%. This is consistent with utilization reports from service providers, who report increases in the number of clients being assessed for treatment, entering one-on-one or group counseling, and entering in-patient residential treatment.

3. Service Priorities

Injection drug using PLWH identified housing assistance and related services as their highest service priority in 2001. Housing services were followed by case management, primary medical care, prescription drug programs and food/meal programs (Table 26).

IDU PLWH were significantly more likely than other consumers to identify housing services as a priority (64% versus 45%). As previously noted, the rate of homelessness in this population is far greater than in non-IDU PLWH. Lack of access to permanent housing can increase the likelihood of relapse, particularly for IDU who are recently discharged from treatment facilities.

**Table 26. Service Priorities: Injection Drug Users
(n=58; 7 missing responses)**

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Housing assistance/related services	37	64%
2	Case management	32	55%
3	Ambulatory/outpatient medical care	31	53%
4 (tie)	Drug prescription program (ADAP)	22	38%
4 (tie)	Dental care	22	38%
6	Food/meals	20	34%
7	Alternative/non-Western therapies	19	33%
8	Client advocacy	18	31%
9	Mental health therapy/counseling	17	29%
10	Counseling (emotional support)	16	28%

As in past years, providers of services to injection drug using PLWH were much more likely than consumers themselves to rate substance use treatment and counseling as a priority service for this population. This may be due to consumers' beliefs that substance use treatment is not an HIV/AIDS-related service or consumer denial about the need for this service. However, focus group participants (each of whom was currently either in recovery or a harm reduction program) stressed the importance of substance use counseling in improving their overall health and emotional well-being.

5. Service Gaps

Injection drug using PLWH identified service gaps that were relatively similar to those reported by other populations. The number one service gap identified by injection drug using consumers was alternative therapies, followed by counseling (peer support), emergency financial assistance, dental care and housing assistance (Table 27).

Unlike previous years, IDU survey respondents were less likely than other consumers to report unmet service needs. The only two services that were more likely to be seen as gaps by IDU were alternative therapies (28% versus 22%, which is not statistically significant) and substance

use treatment (12% versus 3%). Focus group participants noted that they had little trouble accessing substance use treatment once they determined they were ready for it. Each participant noted that they knew several current IDU who were either HIV infected or at high risk of infection who were not yet ready to seek substance use treatment, some of whom were also not accessing primary care for treatment of their HIV.

Table 27. Service Gaps: Injection Drug Users (n=65)

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Alternative/non-Western therapies	18	28%
2	Counseling (emotional support)	11	17%
3	Direct emergency financial assistance	10	15%
4 (tie)	Dental care	9	14%
4 (tie)	Housing assistance/related services	9	14%
6 (tie)	Substance use treatment/counseling	8	12%
6 (tie)	Mental health therapy/counseling	8	12%
8 (tie)	Client advocacy	7	11%
8 (tie)	Legal assistance	7	11%
10 (tie)	Insurance programs	6	9%
10 (tie)	Food meals	6	9%

Providers were in agreement with this sentiment. They noted that increasing numbers of their clients are now using substance use treatment and trying to get addiction under control. However, they reiterated that it may take a very long time for the provider to persuade clients to access treatment, requiring that providers build trust between themselves and the client before this engagement can occur. They also stressed the importance of having chemical dependency services immediately accessible when the client is prepared to receive them. They noted that Ryan White vouchers have been very helpful in avoiding long waiting lists for ADATSA services.

Providers of service to injection drug using PLWH frequently mentioned housing as the main service that their clients were unable to access. Providers noted a lack of affordable housing in general for low income persons in King County, particularly for their clients who are living at or below 100% of poverty level. They also noted a shortage of emergency and transitional programs for clients who are discharged from in-patient facilities. They noted that these clients are at high risk of failing in their attempts to maintain housing because they are likely to relapse into substance abuse.

Although neither consumers nor providers identified a barrier in accessing medical care, providers did note that many of their clients are uncomfortable with the kind of care they receive. Some of this relates to client perceptions that providers will treat them with less respect because of their substance use histories. Providers stated that this used to be much more of an historical

reality, but that in recent years they have seen far fewer cases of ill-treatment of their clients. Nevertheless, the perception lingers and may serve as a barrier to clients receiving care.

5. Access Barriers

IDU respondents to the consumer survey identified similar access barriers as other populations, with lack of information and financial barriers being the two most frequently noted (Table 28).

Table 28. Access Barriers: Injection Drug Users (n=49)

BARRIER	# OF VOTES	% OF RESP.
Lack of information	15	23%
Financial (can't afford it)	10	15%
Eligibility (based on disability status)	5	8%
Haven't asked	4	6%
Eligibility (non-specific)	4	6%

Consumers in focus groups and providers acknowledged that chemical dependency and general life chaos often take priority over health care and social service needs. Thus, services may not be accessed until the client is in severe crisis. Drug injecting clients usually enter into the HIV care system with little awareness of available services and may become over-reliant on the services of case managers or outreach workers to help them access services. Providers also noted that low self-esteem among IDU PLWH can complicate access to care.

“Nobody knows about the virus on the streets, especially the people that are prone to getting it. The addict lifestyle here is totally different then where I came from. Here I say “I have the virus” and other addicts say, “What virus?” People don’t have a clue. (Female IDU PLWH)

Misinformation about services that is circulated among IDU on the street can also be problematic, such as the previously-mentioned belief that medical providers will not give IDU clients appropriate care. Several focus group participants expressed frustration that they were unable to access pain medications, often because the provider felt that these medications would be dangerous when combined with the street drugs that the client was taking. Some participants also felt that providers were less likely to recommend HAART therapy to their IDU clients, although others acknowledged that active substance use made adherence with medication regimens much harder.

Unlike previous years, IDU were no more likely than non-IDU PLWH to identify financial barriers in accessing HIV services. However, because most IDU PLWH are living at or below poverty level, financial concerns in general weigh heavily in their ability buy groceries and clothing and afford transportation. Providers noted that clients who are still actively using substances may opt to use what little funds they have to purchase drugs, alcohol or cigarettes rather than paying for rent, utilities and other necessities. As one provider noted, “For clients who earn their money through drug sales or sex work, time spent waiting for appointments and

seeing social workers and doctors is money lost. Perhaps if they were getting [more financial assistance], they would be able to break the cycle of the daily hustle.”

“My biggest obstacle in looking for housing is my background in the penitentiary. Places like HUD, then tend to want to keep that in front of your face even though you’ve finished the time. Housing has been available to me, but it’s in the danger zone area, it’s right where the drug market is. They’ll put you in one of those places where there is constant drug activity.” (African-American male IDU PLWH)

As in previous years, providers and IDU consumers also noted that housing policies that demand absolute sobriety can pose obstacles. Although sobriety houses are safe and affordable for clients, many programs will not accept clients that are going through methadone treatment. This can be particularly problematic for clients whose chemical dependency counselors have helped them accept a harm-reduction modality, while other service programs promote abstinence.

Providers offered several suggestions about how to improve service delivery and client access for injection drug using PLWH:

- Develop more housing options for IDU similar to the Lyon Building, a 64-unit residential facility primarily for persons multiply diagnosed with HIV/AIDS, chemical dependency and/or mental illness. The harm reduction modality adopted by the Lyon Building allows persons in recovery to work towards sobriety without the danger of being evicted for relapse problems. In particular, one provider suggested a Lyon Building format specifically for female IDU PLWH.
- Identify more funding to increase the number of treatment slots. Trying to find treatment on demand is difficult and detox beds are limited. Creating mobile methadone treatment options would be particularly helpful.
- Offer on-site substance use and mental health counseling in a variety of venues. Develop drop-in sites where homeless IDU can come to “hang out” and receive food, meals and other services.
- Continue to train service providers across the Continuum of Care about harm reduction principles and processes. The more that service providers can accept the harm reduction model, the greater the chance of effective inter-system collaboration. Providers need to develop strong rapport-building skills to ensure that their IDU clients maintain involvement in services.
- Stress the importance of culturally-appropriate care. This includes not only understanding and working with racial and linguistic diversity, but acknowledging that there is a culture of substance-using individuals who may bring different values and health beliefs to the care system.

C. People of Color

“Services are getting harder to access. I think it’s getting worse, just with the challenges around funding. And it’s not about race, it’s about funding. What do I have to look forward to? I’m tired of getting \$10 in food stamps!” (African-American male PLWH)

(NOTE: Information is reported by specific sub-populations of communities of color, based on data from service providers, consumer survey respondents and consumer focus group participants. Data tables include aggregate statistics from consumer survey respondents who identified as African-American (n=62) or Latino/Latina (n=52). The number of American Indians/Alaska Natives (n=14) and Asians/Pacific Islanders (n=13) who responded to the survey is insufficient from which to develop useful data tables for these populations or on which to run tests for statistical significance. As a result, information presented regarding PLWH from these populations is based primarily on key informant provider interviews and focus group responses.)

1. Epidemiologic Profile

In Seattle-King County, as in the United States as a whole, epidemiologic data indicate that HIV and AIDS have disproportionately affected African-Americans, American Indians/Alaska Natives, and Latinos/as as compared to whites or Asian/Pacific Islanders. The racial disparity is even greater among women and children as compared to men.

Status and trends in AIDS cases: Through December 2000, 1,214 people of color residing in King County were reported with AIDS, representing 20% of the 6,096 total AIDS cases. AIDS rates in recent years (1997-1999) demonstrate the epidemic’s disproportionate impact, with rates in African-Americans, Latino/as and American Indian/Alaska Natives being over three times that of whites in King County. AIDS rates in Asian/Pacific Islanders, however, continue to be significantly lower than whites. A comparison of King County 1998 population estimates and reported AIDS cases in King County for the three-year period of 1997-1999 is reported below (Table 29).

Table 29. Comparison of King County Racial Composition with Recent AIDS Case Statistics (1997-1999)

	King County	(% of pop.)	AIDS Cases (1997-1999)	(% of cases)	AIDS case rate per 1000,000 population
White	1,332,575	(80%)	399	(67%)	10.0
African American	88,993	(5%)	97	(16%)	36.0
Latino/Latina	57,716	(4%)	64	(11%)	35.9
Asian/Pacific. Islander	168,188	(10%)	17	(3%)	3.4
Am. Indian/AK Native	18,328	(1%)	18	(3%)	33.0
TOTAL	1,665,800	(100%)	595	(100%)	11.9

Racial disparities are greatest among women and children. In 1997-1999, the average annual rate of AIDS for African-American females (17.3 per 100,000) was 19 times greater than that of whites females (0.9 per 100,000). Also, eight (57%) of the 14 maternally-acquired acquired

pediatric AIDS cases reported in King County through December 2000 were born to women of color.

More African-American and American Indian/Alaska Native men and women acquire HIV from injection drug use as compared to other groups. The percent of AIDS cases by race for selected HIV exposure categories for males and females are given in Table 30.

Table 30. AIDS Cases by Race and Selected HIV Exposure Categories (12/31/00)

MALES (N=5,803)	White	Afr-Am	Latino/a	A/PI	AI/AN
MSM non-injectors	82%	58%	72%	83%	57%
MSM drug injectors	11%	11%	8%	5%	27%
Heterosexual drug injectors	3%	14%	10%	3%	9%
Heterosexual non-injectors	1%	4%	3%	1%	1%
FEMALES (N=293)	White	Afr-Am	Latino/a	A/PI	AI/AN
Drug injectors	27%	34%	6%	0%	71%
Heterosexual non-IDU	51%	37%	63%	38%	24%
Transfusion recipients	8%	4%	6%	13%	0%
Undetermined	12%	21%	13%	50%	6%

HIV seroprevalence: Between 1,600 and 2,340 (midpoint=2,000) people of color residing in King County are estimated to be HIV positive, compared to 4,440 to 6,660 whites. By race/ethnicity, this includes 840 to 1,260 African-Americans, 480 to 720 Latino/as, 120 to 180 American Indian/Alaska Natives, and 120-180 Asian/Pacific Islanders.

In surveys of King County women giving birth from 1989 to 1995 (when the survey ended), the percent of African-American women testing HIV positive (0.3%) was ten times the percent of white women (0.03%).

2. Service Trends

African-Americans: Providers of services to African-American PLWH reported that their client caseloads are approximately two-thirds male, with no significant changes in the gender make-up in the past several years. Similar to epidemic figures, African-American survey respondents were significantly more likely than whites to be female (37% versus 8%) and identify as heterosexual (45% versus 12%). African-American survey respondents were also more likely than whites to report incomes under 100% of Federal Poverty Level (50% versus 32%) and Seattle, rather than East or South King County, residency (85% versus 76%).

“Why do people have to be unbelievably poor to get assistance? I struggle check to check. I hardly ask for help and yet when I get up the nerve to do just that, I’m embarrassed with a “you don’t qualify” response. My biggest fear is what am I going to do when I can’t work and I don’t have any coverage and I can’t afford any.” (African-American female PLWH)

Although providers note that increasing numbers of their African-American clients are currently taking HIV-related medications than in past years, adherence issues continue to be a growing

problem. Providers noted that access to HIV-related medications is not a problem, but that many of their clients do not want to start HAART regimens, either because they do not trust the medications or are wary of side effects. However, one provider noted that her African-American clients have become better at addressing adherence issues with their medical providers, and are less likely to discontinue their medications without first discussing this issue with their providers.

Despite these positive changes, African-American PLWH survey respondents continue to be significantly less likely than whites to be taking all forms of HIV-related medications. This includes lower rates of taking antivirals (63% versus 83%), protease inhibitors (35% versus 56%) and medications to treat or prevent opportunistic infections (31% versus 47%). Of PLWH who reported taking at least one form of HIV-related medications, African-Americans were significantly more likely than whites to report having adherence problems (42% of African-American PLWH versus 32% of whites).

Several other differences emerged regarding health status between African-American and white survey respondents. African-Americans were statistically more likely to report themselves as HIV+, without symptoms (42% versus 26%) and almost four times less likely to have been diagnosed with AIDS based on opportunistic infections (8% versus 31%). However, African-Americans were also significantly more likely than whites to report not knowing their current T-cell counts (24% versus 7%) nor their viral loads (26% versus 9%).

African-American survey respondents were four times more likely than whites to report having been homeless in the past year (24% versus 6%). Providers of outreach services to African-American PLWH noted seeing an increase in the number of homeless clients they are encountering and helping engage into services.

No significant differences emerged on the consumer survey regarding rates of mental illness and substance use reported among African-American versus white PLWH. However, providers reported that large and growing numbers of their clients suffer from depression. Many clients have long-term histories of mental health problems, although many are in denial about the need to seek professional help. Substance use issues continue to be widespread among African-American PLWH, although providers noted a slight decrease in the number of clients who are using and a slight increase in the number who are in (or seeking) treatment.

In general, African-American survey respondents reported higher utilization rates of most services than did white consumers. In previous years, African-American PLWH were significantly less likely than whites to use outpatient medical care. On the 2001 survey, this difference was no longer statistically significant (90% of African-Americans using primary medical care versus 94% of whites). However, African-American consumers were more likely to rely on the Washington State AIDS Drug Assistance Program for their HIV-related medications than whites (61% versus 51%).

African-Americans were significantly more likely than whites to use transportation services (50% versus 29%), peer counseling services (66% versus 55%), emergency financial assistance (48% versus 38%), health education/risk reduction programs (35% versus 15%), and housing assistance (61% versus 50%). The single service that was more likely to be used by whites than

African-Americans was alternative, non-Western therapies (41% of whites versus 31% of African-Americans).

Of special note is the increase in HIV+ African refugees who have re-settled in King County. The largest groups are from Ethiopia and Eritrea, but almost all West African countries are represented. Approximately one-third of these clients are women. Most of the African PLWH live in the Rainier Valley in Seattle, with the remainder located in South King County.

Providers of services to African refugee PLWH report that their clients are generally in good health. Once introduced to the HIV care system, the clients have had good access to medical care and prescription medications. Co-morbidities such as mental illness and substance use are rare in this population.

Latino/Latinas: Providers of services to Latino/a PLWH reported that their client caseloads are predominantly male, although a growing number of Latinas have begun to enter the HIV care service system in recent years. While the difference is not as marked as with African-American survey respondents, Latino/a survey respondents were significantly more likely than whites to be female (19% versus 8%) and identify as heterosexual (29% versus 12%).

Latino/a survey respondents were more likely than all other populations to report incomes under 100% of Federal Poverty Level (71% of Latino/as versus 32% of whites and 52% of African-Americans). Providers noted that a large percentage of their clients have no income at all and are entirely dependent on government assistance. Latino/as were also significantly more likely than other consumers to report living in South and East King County (35%, versus 24% of whites and 15% of African-Americans).

Providers reported that their clients' health has generally improved during the past two years, with most clients being HIV+ and asymptomatic. Although clients may report non-disabling HIV-related symptoms, morbidity and mortality seem to have decreased in this population since 1999. As with African-American clients, providers noted that increasing numbers of their Latino/a clients are currently taking HIV-related medications than in past years. The percent of Latino/a survey respondents who report taking HIV-related medications has remained fairly constant from 1999, with no significant differences emerging between whites and Latino/as regarding medication status.

Providers noted that adherence problems continue to be common among their Latino/a clients. Providers stressed the importance of providing ongoing support and motivation to their clients to assist them with medication adherence. Several noted that long-term adherence has now been achieved for many clients, crediting improved communication between medical and social providers and Latino/a clients. As a result, of all PLWH who reported taking at least one type of HIV-related medication, a smaller percentage of Latino/a survey respondents reported adherence problems (30%) than did whites (32%) or African-Americans (42%).

Similar differences emerged regarding health status between Latino/a and white survey respondents as were noted between African-American and white PLWH. Latino/as were statistically more likely to report themselves as HIV+ without symptoms (40% versus 26%) and

less likely to have been diagnosed with AIDS based on opportunistic infections (21% versus 31%). However, Latinos/as were also significantly more likely than whites to report not knowing their current T-cell counts (23% versus 7%) nor their viral loads (31% versus 9%).

Latino/a survey respondents were over three times more likely than whites to report having been homeless in the past year (21% versus 6%). Providers of outreach services to Latino/a PLWH noted that as many as one-third of the clients had been homeless at one time or other during the past year. However, case managers with large Latino/a caseloads noted that their clients were successfully maintaining housing stability after placement in HIV-related housing facilities.

Latino/a PLWH were significantly less likely than white survey respondents to report mental illness and substance use. Only 15% of Latino/as reported having been diagnosed with mental illness, versus 33% of whites. However, providers reported that depression is fairly common among their clients. They expressed a need to educate Latino/a PLWH about mental health issues and services, noting that cultural differences in the ways which one understands mental illness often keep their clients from seeking services.

Substance use seems to be increasing in the population of Latino/a PLWH, with providers noting that alcohol abuse is widespread. Many clients are in denial about their use, however. As one provider noted, “If it’s not a crime, it’s not a problem.” The percentage of Latino/a survey respondents who reported using injection drugs was significantly lower than for either whites or African-Americans (2%, versus 8% and 8%, respectively), as was the percentage of Latino/as who reported use of other street drugs (6% versus 15% and 21%, respectively).

In most service categories, Latino/a survey respondents reported similar utilization rates as white consumers. In previous years, Latino/a PLWH were significantly less likely than whites to use outpatient medical care. On the 2001 survey, this difference was no longer statistically significant (87% of Latino/as using primary medical care versus 94% of whites). However, Latino/a consumers were significantly more likely than whites to use treatment adherence support services to assist them in taking their medications as prescribed, particularly from case managers and client advocates (40% of Latino/as using this service versus 27% of whites).

Latino/as were significantly more likely than whites to use housing services (40% versus 27%) and health education/risk reduction programs (25% versus 15%). As previously noted by providers, their Latino/a clients did not tend to be connected to mental health services. This statement is supported by survey data, which reveal that Latino/as are significantly less likely than whites to use mental health therapy and counseling (29% versus 50%). The single other service that was more likely to be used by whites than Latino/as was dental care (73% of whites versus 62% of Latinos/as).

American Indian/Alaska Natives: Providers of service to American Indians and Alaska Natives report that their caseloads are predominantly comprised of males, although increasing numbers of women have entered the system in recent years. The majority of American Indian clients live below the poverty level, and have been living in poverty most of their lives. Transmission risk among men is predominantly through homosexual activity, although men may not self-identify as gay or bisexual. Among women, heterosexual transmission is most common. Demographic

indicators among the relatively small number of American Indian survey respondents are consistent with provider reports.

Providers report chronic alcohol and drug use among the majority of their American Indian PLWH population, with heroin and cocaine being the most commonly used drugs. Increasing numbers of clients have sought treatment in the past two years, including entering harm reduction programs and methadone treatment. Providers also report that the majority of their American Indian PLWH clients have mental health issues. More clients are accessing mental health services than in previous years. A higher percentage of American Indian consumer survey respondents report histories of mental illness, injection drug use and use of other street drugs and recent incarceration than other consumer sub-populations.

Providers reported that their clients' health has generally declined during the past two years, with more clients experiencing HIV-related health symptoms. This is particularly true of female American Indian PLWH. Providers report an increase in the number of clients who are progressing from HIV+ to AIDS diagnoses, including long-term survivors whose health is now failing.

Providers and focus group participants noted that access to primary care is good when the consumer is ready to accept it. Most of the American Indian focus group participants reported learning they were HIV+ in non-medical settings, such as in jail, at homeless shelters or through drug treatment facilities. In several cases, the knowledge of their HIV serostatus was accompanied with an AIDS diagnosis. Current access to HIV-related medications is reported as good, although adherence problems are common. Providers noted that cultural issues regarding taking Western medications complicate adherence with HAART therapy.

As noted in previous assessments, a distinction exists between American Indian/Alaska Natives who are reservation-identified (having been born, raised and/or currently living on tribal lands) versus those who are more acculturated into the mainstream. This distinction may influence clients' willingness to accept non-Indian provided services, trust in non-Indian providers and overall knowledge about HIV. For reservation-identified Indians, developing trust in an unfamiliar provider and/or service system may be a lengthy process. Nevertheless, providers reported that their American Indian clients are more willing to accept referrals to non-Indian service providers than in past years. American Indian/Alaska Native survey respondents reported similar rates of service utilization as other populations.

Asian/Pacific Islanders: Demographic indicators for A/PI PLWH remain relatively unchanged during the past two years. Providers report that their A/PI clients are almost exclusively MSM, with relatively few cases attributed to injection drug use. This is consistent with the limited response to the consumer survey, with almost all of the thirteen A/PI respondents being males who report MSM transmission risk. Clients represent a wide spectrum of Asian nationalities and languages, including Chinese, Vietnamese, Filipino, Korean, Laotian, Japanese, Samoan, Hmong and native Hawaiian. Although most clients speak at least limited English, language barriers are present for new arrivals to the United States. Most clients are low income or below the poverty level.

Providers reported that many of their clients have remained in stable health during the past two years, with very little severe HIV-related illness. Access to HIV medications is not a problem, although cultural distrust of HIV medications may exist for newly-arrived A/PI. Eleven of the thirteen A/PI survey respondents are currently taking some form of HIV medication, with approximately half reporting adherence problems.

Providers noted that co-morbidities among their A/PI PLWH clients are relatively low. Some clients suffer from depression, but other mental illness diagnoses are rare. As previously noted, substance use, including injection drug use, is also uncommon in this population. A/PI survey respondents were also less likely to be homeless than other PLWH of color.

As noted in previous needs assessments, service utilization patterns for A/PI PLWH seem to be dependent on the client's level of acculturation into the mainstream. Asian/Pacific Islanders who are more integrated into the larger community and who do not have language and cultural barriers are reported as seeking services from a wide variety of HIV/AIDS service providers. Those clients who are first generation A/PI are more likely to restrict their services to agencies targeting Asian communities.

The limited number of A/PI survey respondents reported higher utilization rates in most service categories than other populations. Utilization rates were particularly high for medical care, case management, client advocacy, Washington State's AIDS Drug Assistance Program and emergency financial assistance.

3. Service Priorities

African-Americans: African-American survey respondents ranked housing assistance and housing related services as their number one service priority (Table 31). Case management tied with dental care as the second highest service priority, followed by primary medical care, client advocacy and insurance programs. Within the category of client advocacy, the highest prioritized service components were medical information about HIV/AIDS (23%) and benefits counseling, other than by a case manager (21%).

Continuing a trend observed in previous assessments, African-Americans were significantly more likely than whites to prioritize housing assistance (56% versus 42%). Providers noted that securing low income housing is an issue for many of their clients. Even if subsidies are increased, housing can still be difficult to access due to prior criminal records and current substance use. As previously noted, African-American consumers were also less likely than whites to be AIDS disabled and therefore may not qualify for housing based on disability status.

African-American PLWH were less likely than whites to prioritize outpatient medical care, with only 50% of respondents listing this service as a priority as opposed to 69% of white PWLH. This may be related to the fact that African-American respondents were more likely than whites to report that they were HIV+ and asymptomatic and significantly less likely to have been diagnosed with an opportunistic infection.

Table 31. Service Priorities: African-Americans (n=54; 8 missing response)

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Housing assistance/related services	30	56%
2 (tie)	Case management	29	54%
2 (tie)	Dental care	29	54%
4	Ambulatory/outpatient medical care	27	50%
5	Client advocacy	26	48%
6	Insurance programs	23	43%
7	Food/meals	20	37%
8	Direct emergency financial assistance	18	33%
9	Counseling (emotional support)	16	30%
10	Drug prescription programs (ADAP)	14	26%

Among African immigrant PLWH, providers noted that case management is extremely important. These clients enter the system with little or no knowledge of available services. In many cases, they are unfamiliar with HIV medical care in general. Legal assistance in coping with immigration issues is also of high importance to this population.

Latino/Latinas: Latino/a survey respondents ranked housing assistance and housing related services as their number one service priority (Table 32). This was followed by case management, dental care, primary medical care and client advocacy. Within the client advocacy category, the most highly prioritized services were medical information about HIV/AIDS (21%), interpreter services (17%) and benefits counseling (15%).

Latino/a consumers were significantly more likely than whites to prioritize housing assistance and related services (69% versus 42%). Providers noted that housing needs among their clients have increased in recent years, particularly due to the increasing number of non-resident clients who have arrived in King County. Seattle Housing Authority is now checking immigration status for all applicants, making it more difficult for persons without legal standing to qualify for housing assistance. Additionally, as noted previously, many Latino/a PLWH have low or no incomes, and cannot afford to cover security deposits for rental apartments.

Table 32. Service Priorities: Latino/Latinas (n=48; 4 missing response)

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Housing assistance/related services	33	69%
2	Case management	28	58%
3	Dental care	27	56%
4 (tie)	Ambulatory/outpatient medical care	26	54%
4 (tie)	Client advocacy	26	54%
6	Insurance programs	25	52%
7	Direct emergency financial assistance	23	48%

8	Drug prescription program (ADAP)	16	33%
9	Legal assistance	13	27%
10	Alternative, non-Western therapies	11	23%

Latino/a consumers were significantly more likely than whites to prioritize client advocacy services (54% versus 30%). Latino focus group participants noted that information about HIV disease and medications is difficult to obtain within their communities. Many of the participants reported that they were initially reliant on “word-of-mouth” referrals from friends and relatives in order to access medical care and social services when they arrived in King County. They also noted that they prefer to receive information about services from peers who are both linguistically and culturally attuned to their needs.

“There’s a lot of people from other countries that need help and don’t know how to get it because they are afraid of Immigration. If HIV can’t be passed so easily, why have so many immigrants never been able to see their own family because they cannot come back to the USA? Americans can go and come back to many places. Why can’t illegals do the same?”
(Latino male PLWH)

Latino/as were also significantly more likely than white PLWH to prioritize emergency financial assistance (48% to 27%), insurance programs (52% versus 39%) and legal assistance (27% versus 14%). Providers noted that the primary legal need for their clients is for immigration assistance. They reported that many recently-arrived clients may not understand that services are available to assist them with immigration issues, and may believe that any contact with the legal system will lead to other services being denied them.

American Indian/Alaska Natives: In general, the limited number of American Indian survey respondents identified similar service priorities as other consumer sub-populations. These included housing assistance, peer emotional support, case management, and client advocacy. Although American Indian respondents were just as likely as other consumers to be accessing medical care, they were significantly less likely than other PLWH to prioritize this service, with only three of the fourteen respondents listing primary care as a service priority. Focus group participants stated that they each knew other HIV+ American Indians who were not seeking medical care for their HIV, due to distrust in the system or denial about the severity of their illness.

“For some people, look at how much they’ve got going on besides HIV: they’re hungry, they need a place to sleep, they look for drugs and alcohol. They don’t have time for health. I know myself, I’d only go [for medical care] if I was really sick. For me, I didn’t go until I had abscesses.” (Female American Indian PLWH)

Providers of services to American Indians and Alaska Natives noted that case management and client advocacy were extremely important for their clients. Most of their clients are dually or triply diagnosed (HIV, mental illness and chemical dependency), as well as needing assistance with housing, financial and insurance issues. As a result, these clients require more time and resources than other clients in order to help them access and maintain services.

Asian/Pacific Islanders: The limited number of Asian/Pacific Islander PWLH identified similar service priorities as other consumer sub-populations. The top service priority identified by A/PI PLWH was ambulatory care, followed by drug prescription programs, case management and insurance programs.

*“It’s so hard to say what’s important to me. All of the services are important for me!”
(Female Asian/Pacific Islander PLWH)*

Only one of the thirteen A/PI respondents identified peer emotional support as a priority. Providers have noted that peer support is particularly difficult to generate in the A/PI PLWH community, due to the wide range of languages spoken and confidentiality concerns about being identified as HIV+ in small and relatively tight-knit communities.

In particular, providers stressed the importance of delivering services in a culturally competent manner, which takes into account the client’s culture of origin. Because the range of languages spoken in the Asian/Pacific Islander communities is extensive, this requires that providers have access to a broad range of Asian language interpreters.

4. Service Gaps

African-Americans: African-American survey respondents were similar to other populations in their identification of service gaps. African-American PLWH ranked emergency financial assistance, housing assistance, client advocacy, counseling (peer emotional support) and food/meal programs among their top five service gaps (Table 33). Within the client advocacy category, African-Americans noted particular gaps in benefits counseling (10%) and peer or client advocacy (10%). Within the counseling category, the largest gap emerged in one-on-one peer support (18%).

In 1999, African-American PLWH were significantly more likely than whites to identify gaps in almost a third of all categories. In 2001, this disparity seems to have decreased in most areas. The only categories in which African-American consumers identified significantly greater gaps than whites are case management (11% versus 3%) and food/meal programs (16% versus 8%). As one provider of services to African-American PLWH noted, “Clients may complain about problems with quality and services [in food programs], but no one is going hungry. The issue may be the type of food offered.”

Both providers and consumers voiced concerns about the lack of African-American case managers in the King County Continuum of Care. Several clients noted that, while they appreciate the services their case manager has provided, they do not feel the same sort of bond with their case managers as described by other consumers. White case managers may not be well acquainted with African-American culture, and may not respond well to different communication styles. As a result, African-American clients may be more reliant on assistance from peer advocates than other populations.

Table 33. Service Gaps: African-Americans (n=62)

RANK	SERVICE	# OF VOTES	% OF RESP.
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1	Direct emergency financial assistance	15	24%
2	Housing assistance/related services	13	21%
3 (tie)	Client advocacy	12	19%
3 (tie)	Counseling (emotional support)	12	19%
5	Food/meals	10	16%
6	Alternative, non-Western therapies	9	15%
7	Case management	7	11%
8	Referral	6	10%
9 (tie)	Adult day health	5	8%
9 (tie)	Dental care	5	8%

Interpreter services emerged as a major gap for African immigrant PLWH. Because these are relatively new populations to emerge among the HIV cases in King County, the pool of available interpreters who speak Amharic, Somali and other West African languages is more limited than for other linguistic minorities. Additionally, concerns about confidentiality may lead clients to refuse to work with certain interpreters if those interpreters are closely connected with the client's community.

Finding appropriate legal assistance can also be challenging for providers working with the refugee population. The legal issues surrounding re-location to the United States are complex, and made more difficult due to HIV status. Providers also noted that identifying culturally-appropriate food and meal programs for their African clients is very difficult.

Latino/Latinas: Consistent with rankings from the 1999 needs assessment, Latino/a survey respondents ranked emergency financial assistance as the largest service gap in the Continuum of Care, followed by counseling (emotional support), housing assistance, client advocacy and legal assistance (Table 34). Latino/Latino consumers were significantly more likely than whites to report gaps in over half of all service categories.

Table 34. Service Gaps: Latino/Latinas (n=52)

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Direct emergency financial assistance	20	38%
2	Counseling (emotional support)	19	37%
3	Housing assistance/related services	18	35%
4	Client advocacy	17	33%
5	Legal assistance	15	29%
6	Adult day health	14	27%
7	Alternative, non-Western therapies	13	25%
8	Dental care	12	23%
9	Referral	11	21%

10	Food/meals	10	19%
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The largest disparity between Latino/a and white PLWH emerged in the category of adult day health, with 27% of Latinos/as reporting a service gap versus 2% of whites. Although the provider agency of adult day health services has increased the number of Spanish-speaking staff in recent years (and reported an increase in Spanish-speaking clients), clients may still feel uncomfortable in social and therapeutic settings which are primarily Anglo. One provider noted that several of her clients have experienced improved health and no longer meet the medical criteria necessary to qualify for the program.

Other major gap disparities between Latino/as and white PLWH exist the in the categories of counseling (emotional support) (37% versus 17%), housing assistance (35% versus 16%), legal assistance (29% versus 8%) and client advocacy (33% versus 18%). In most cases, focus group participants pointed to language and cultural barriers that prevented them and their peers from fully accessing these services. Providers noted that their clients may individually express a desire for peer support (particularly support groups), but are unlikely to participate in group support activities. As previously noted, immigration and language issues contribute to the gap in housing assistance and legal services.

As in previous assessments, access to Spanish-speaking providers was also identified as a service gap across the continuum of HIV services. Focus group participants who were not proficient in English expressed a desire to have services provided in their native language, rather than through an interpreter. They noted that it is rare to find more than one or two Spanish-speaking staff at agencies, but acknowledged that progress is being made. Additionally, several focus group participants called attention to the scarcity of culturally competent Spanish-speaking case managers. They noted that having a case manager who is bilingual is not enough to ensure that effective communication occurs between provider and client. As a result, several participants stated that they felt that they were not given sufficient information about available services and eligibility requirements.

American Indian/Alaska Natives: Peer emotional support and housing assistance emerged as the largest service gaps among American Indian PLWH. Focus group participants identified concerns that one-on-one and group support was not available to them. They expressed frustration that no groups existed specific to the needs of American Indians living with HIV, since the termination of the support group at the Seattle Indian Health Board. They felt that HIV/AIDS agencies serving persons of color do not seem to be as inclusive of American Indians as other populations and that mainstream HIV/AIDS organizations target their services to gay, white men.

Participants expressed dissatisfaction with lengthy waiting lists and lack of affordable housing options. Many of the participants have had transient housing arrangements, moving in and out of Seattle and other parts of King County. Several have returned to the reservation for periods of time, but stated that they were worried about news of their HIV status becoming public in their community. As a result, participants tend to “couch surf” with families and friends in the absence of long-term housing arrangements. Providers noted that client histories of substance use and incarceration also contribute to the difficulty in accessing permanent housing.

Asian/Pacific Islanders: Due to the small number of surveys returned from A/PI consumers, no patterns emerged regarding identifying service gaps. No service was listed as a gap by more than three of the thirteen A/PI respondents.

As with Latinos and American Indians, providers stated that service gaps were largely dependent on the degree of integration into the mainstream culture exhibited by their clients. For clients who are familiar with and comfortable using mainstream HIV/AIDS services, few gaps exist. However, for those who are recent immigrants or for whom English is not their first language, obtaining medical information about HIV can be difficult. Clients have stated that their doctors may not have the time to discuss their treatment and provide information on HIV/AIDS that is fully comprehensible to them. It is also rare that written materials are translated into the large number of Asian languages spoken in King County, which also limits consumer knowledge about the disease, treatments, and available services.

Providers also noted gaps in access to culturally-specific food and meal programs and immigration advocacy. Due to the low numbers of A/PI PLWH, agencies may not be able to devote specific resources to Asian groceries and meals. One provider suggested expanding the grocery voucher program to include Uwajimaya, a grocery and retail store in the International District in Seattle. Immigration issues can be very complex and anxiety-ridden for non-resident HIV+ PLWH, but obtaining legal assistance from professionals who are familiar with both HIV issues and the client's culture of origin is difficult.

5. Access Barriers

African-Americans: In general, African-American survey respondents reported similar access barriers as other populations. The most common barrier identified by African-American PLWH is lack of information about available services (Table 35). Although inability to afford needed services was the second most common barrier identified by African-American consumers, African-Americans were significantly less likely than whites to report financial barriers (10% versus 21%). This may be due to differences in average annual incomes, as a higher percentage of African-American consumers appear to qualify for Ryan White-funded programs than do whites.

Despite the fact that none of the African-American survey respondents reported that poor service quality was an access barrier, this was the major concern expressed by participants in the African-American focus group regarding several services. In particular, several focus group members stated dissatisfaction with the quality of medical care, case management, financial assistance and insurance programs they had received.

Table 35. Access Barriers: African-Americans (n=62)

BARRIER	# OF VOTES	% OF RESP.
Lack of information	16	26%
Financial (can't afford it)	6	10%
Haven't asked	5	8%
Eligibility (based on financial status)	4	6%

Waiting list; not enough services	4	6%
Conflicts with schedule	4	6%

Providers of services to African-American clients echoed these sentiments. Providers reported that several of their clients feel that they have been denied services because of their race, or that the services they have gotten are inferior to those given white PLWH. As in previous years, providers and focus group participants reported that African-American PLWH are generally less connected to the overall service system, and have unequal access to information about available services and how decisions about eligibility are determined.

Providers also noted that convincing clients of the importance of consistent, ongoing medical care is a challenge for them. This is particularly true of very low income clients and those with substance use backgrounds. Medical care often does not assume a priority in these clients' lives, and the provider needs to help the client realize that a commitment to ongoing care is necessary.

As previously noted, language differences are the primary access barrier for the population of African immigrant PLWH. Not only is it difficult to find providers and interpreters who speak the various West African languages necessary to serve this population, but information and materials about HIV are generally unavailable as well.

Providers noted that cultural stigma surrounding HIV is a very difficult barrier to overcome. In some cases, husbands and wives have not even told each other about their HIV status. As a result, clients can be very isolated, even within their own communities. Due to language and cultural barriers, access to support from the broader PLWH population is rarely possible. This often entails case managers having to make more frequent home visits than with other clients, since the client may be afraid to be seen in a clinical or social service setting associated with HIV.

Latino/Latinas: Latino and Latina respondents to the consumer survey expressed similar access barriers as other populations. No statistically significant differences emerged in the types of access barriers identified by Latino/a survey respondents versus those identified by other populations (Table 36).

Table 36. Access Barriers: Latinos/Latinas (n=52)

BARRIER	# OF VOTES	% OF RESP.
Lack of information	15	29%
Eligibility (non-specific)	4	8%
Financial (can't afford it)	3	6%
Language barriers	3	6%
Waiting list; not enough services	3	6%
Eligibility (based on disability status)	3	6%

Based on information from focus group participants and service providers, cultural and linguistic differences continue to be significant barriers for Latino/a PLWH. Providers and consumers noted the importance of understanding Latino cultural norms in order to be able to offer culturally sensitive services to this population. These norms include the high value placed on family, the importance of religion, and cultural norms against talking directly about sex and sexuality. This is particularly true of clients who are recent arrivals to the United States, and may be having trouble adjusting to the dominant culture.

“When a person speaks Spanish, but inside is an English-speaking person trying to say something from Spanish to English, they can turn one word around and change the whole meaning of a sentence. It is very frustrating for all of us to get through to someone, knowing that person has said something you didn’t say. Services are so difficult for us to access because of the fact that we can’t find someone who is Latino – not just an American who speaks Spanish.” (Latino male PLWH, native Spanish speaker)

Language barriers continue to exist for the growing numbers of clients who have limited or no English proficiency. Providers noted that some clients might be ashamed to admit that they cannot understand English, and may sit through appointments without having actually comprehended what was being discussed. Focus group participants noted that they feel cut off from much of the information that is available to English-speaking PLWH, particularly if they are unfamiliar with the ways in which services are provided in King County as opposed to their country of origin.

Providers noted that disclosure and confidentiality may be major issues for their clients, especially for those who are new to the country or newly diagnosed. If clients are undocumented or fearful of being deported due to their HIV status, they may be unwilling to seek services. They may be fearful of bureaucracy and resistant to filling out forms at service agencies that identify them as HIV+ and/or as without legal standing.

Latino/a PLWH may also experience extreme feelings of isolation. As one provider noted, “HIV has alienated clients from their country, their family, and their community. The new culture is very difficult to adopt, leaving them with a ‘floating feeling,’ like they don’t belong anywhere.” Many clients have not shared their sexual history or their HIV status with their close friends or family. Additionally, if Latino male clients are not gay-identified, they may feel uncomfortable in group settings or at agencies that they perceive as gay-oriented.

American Indian/Alaska Natives: Providers and focus group participants identified lack of Indian-specific programs and cultural barriers at mainstream agencies. Due to historical persecution and disenfranchisement, many American Indian clients lack trust in mainstream agencies and providers. Mainstream providers may lack sensitivity to American Indian spiritual concepts, family/kinship systems, and communication styles.

“We all basically know each other. If we don’t know somebody by name, we know their cousins and family. If you go knocking on the door, their uncles and aunts are sitting there. Other family members will want to know. They’ll just shut the door and be shamed. They’ll be like, “No! Nobody has it here!” (American Indian female PLWH)

Focus group participants noted that internal cultural barriers may inhibit American Indians from accessing HIV care and services. They stated that issues of shame, fear and rejection may keep Indian PLWH from reaching out for help in their community. As a result, outreach and prevention education on reservations is very difficult. If Indians leave the reservation to seek services, they are often unaware of available resources and may not know where to turn for assistance.

Providers also noted that many of their clients are homeless, and experience all of the access barriers related to not having a permanent residence. These include difficulty in maintaining contact with case managers and other service providers, unsanitary living conditions, inability to attend to matters of basic hygiene, and lack of space to store and/or refrigerate medications.

Asian/Pacific Islanders: Providers of services to Asian/Pacific Islander PLWH identified many of the same access barriers as providers of service to Latinos, with cultural and language barriers being most significant. Cultural norms about disease and treatment may inhibit clients from seeking services and/or complying with medication regimens unless they are very ill.

One provider noted that “the system lumps all Asians and Pacific Islanders together.” In reality, providers must recognize that cultural norms, health beliefs and treatment systems differ between the various Asian and Pacific Islander communities. Assuming that all A/PI clients share common values and attitudes can undermine provider attempts to effectively communicate with and serve their clients.

Providers suggested several solutions for overcoming access barriers for PLWH of color:

- Be more aware of cultural diversity and sensitivity issues in all settings. This includes increasing the number of providers who are persons of color, developing more effective and consistent linkages between the HIV care system and other agencies that target communities of color, and providing information and training to mainstream providers about how to better serve their clients of color. Several providers noted that models for technical assistance in these areas exist in other states (such as California and Florida) and that the King County Continuum of Care should take advantage of the expertise developed in other parts of the country.
- Develop and/or expand peer support programs for PLWH of color. Persons of color who discover that they are HIV+ may not immediately want to involve themselves in the mainstream medical and social service systems. They would benefit from meeting other members of their communities who share their language and belief systems and who can help them understand the system. This will ultimately help mainstream providers, as peer advocates can help provide linkages to the system and allay fears or suspicions on the part of new clients.
- Develop improved outreach strategies to provide information and education about HIV/AIDS and available services in ethnic communities. Do not assume that communities of color (and providers within these communities) are as knowledgeable about the HIV/AIDS Continuum

of Care as the majority of gay white male clients. Service providers may need to go into the community and identify potential clients, as opposed to waiting for clients to come to them.

- Make medical and social service appointments more flexible to acknowledge different concepts of time and access issues in non-white populations.
- Improve the capacity of agencies serving persons of color to provide more effective HIV-related services. This includes the provision of technical assistance as well as increased funding for these agencies.
- Whenever possible, hire staff who are bi-cultural, rather than merely bi-lingual.
- Educate case managers about immigration issues. Ensure that linkages exist between HIV service providers and legal experts who understand the complex issues regarding relocation and re-settlement.
- Ensure that staff at key service access points (counseling and testing sites, community clinics, case management agencies) have easy access to interpreters. Ensure that agencies earmark funding for interpreter services in their program budgets.
- Ensure that non-English language written materials are readily available, culturally sensitive, and created to effectively address persons with limited reading skills.

D. Women

"I was diagnosed at [a community clinic]. The woman said, "Why do you need to worry about HIV?" They went ahead and cured my yeast infection. Then they sat me down in a conference room and said, "You're HIV+." I got the news from the receptionist." (White female PLWH)

1. Epidemiologic Profile

In King County, women represent a relatively small proportion of the total HIV infections and AIDS cases. However, the proportion of cases in women has increased in recent years, a trend that is expected to continue. Women with HIV/AIDS tend to be younger than men, and are significantly more likely to have acquired HIV through heterosexual contact. Women of color are disproportionately affected.

Status and trends in AIDS cases: Through 6/30/01, there have been 318 cumulative AIDS cases diagnosed in King County females. AIDS cases in women have risen from fewer than ten cases per year in the 1980's to a peak of 35 cases in 1995. Since 1995, the number of women diagnosed with AIDS in King County has decreased slightly or remained constant. However, the proportion of all reported cases that are women has risen consistently from 1-2% of cases in the 1980's to 10-12% in recent years.

Nearly half (47%) of women with AIDS in King County were reported as having acquired HIV through heterosexual contact, 31% through use of injection drugs, 7% by blood transfusion, and 16% by undetermined exposure. In King County, the rate of AIDS among African American and American Indian/Alaska Native women is over ten times higher than in white women and the rate among Latinas is twice that of white women.

Population sizes: In King County, for 2001 the total female population is approximately 906,700. The estimated number of women who are drug injectors or sex partners of injectors is 9,000. The total estimated number of HIV positive women in King County is between 350 to 550.

HIV seroprevalence: In the Survey of Childbearing Women in King County, conducted from 1989 to 1995, 0.04% of the over 123,000 women tested were HIV positive. Among women tested at the King County Sexually Transmitted Disease (STD) Clinic in 1988-1999, 0.3% tested positive, while 1.4% of women tested at drug treatment centers during the same time frame were HIV positive.

2. Service Trends

Demographic trends related to female consumers continue along similar lines as noted in the past two needs assessments. Providers in almost all service categories reported increases in the numbers of women accessing services. Providers noted that the population of women with HIV is growing older, with the majority of clients in their 30's and 40's. Increasing numbers of younger women are also seeking services, especially adolescent girls between the ages of 16 and 21, several of whom are pregnant.

Heterosexual transmission remains the main transmission risk reported by clients. Self-reported injection drug use-related transmission has declined somewhat, but providers note that it is often difficult to distinguish between IDU transmission and transmission due to sexual contact with male IDU's.

As reported in previous years, King County providers are seeing female clients from across the state of Washington. Although most King County female PLWH are Seattle residents, providers are seeing growing numbers of their female clients relocating to South King County due to financial pressures, as well as small increases in the number of female clients living in East King County. Providers also noted that they are seeing an increase in homeless female PLWH, particularly among Latina and American Indian women.

Providers report that the overwhelming majority of their female clients are living at or near the poverty level, particularly those with dependent children. Most of these clients rely on government-supported medical care and financial assistance, much of which has been accessed through their children's coverage. A growing number of low-income female PLWH are involved in the "Welfare to Work" program, but in many case these women are scheduled to run up against their time-limited eligibility.

Service providers report that high percentages of their female clients are multiply diagnosed (HIV, mental illness and/or chemical dependency). Providers of services to women report that upwards of 60% of their female PLWH caseloads have been diagnosed with some form of mental illness, with depression being the most common disorder. Diagnoses of schizophrenia and bipolar disorder are also increasing in this population. Twenty-nine percent of female survey respondents reported that they had been diagnosed with mental illness.

Substance use continues to have a significant impact on the lives of female PLWH. Providers noted that over half of their female clients have histories of substance abuse. Multi-drug use is prevalent, particularly crack cocaine and heroin. More clients are now enrolled in methadone treatment and harm reduction services, in general. Providers noted, however, that progress within the "Welfare to Work" program is often complicated by treatment recovery activities.

Consistent with epidemiologic trends and recent assessment reports, service providers who work with HIV+ women note that a high proportion of their client caseloads are women of color. Providers report that they are seeing increasing numbers of women from all racial categories, particularly African-Americans, Latinas and American Indian women. During the past two years, providers noted that women from the growing refugee populations in King County are beginning to utilize services after ongoing attempts to engage them.

As noted in previous assessment reports, female survey respondents were statistically less likely than males to have received AIDS diagnoses (38% versus 57%). Women were also significantly more likely to report T-cell counts above 200. However, service providers report seeing increases in the number of women presenting with HIV-related symptoms, rising numbers of HIV-related deaths and increasing failures with HIV medications. As one provider noted, "Women are not getting enough medical care." In many cases, these women have relied on generalists or OB/GYN's for their care, and these providers may have failed to diagnose HIV-related symptoms until the women have progressed far into their illness.

"I have Medicaid and Medicare insurance. Every time I want my medication, I have trouble with my spend-down. The first of the month, I am on spend-down. And about every six months, I cannot get my medication. They lose paperwork, or give you some other excuse. So then I have to go out and try to spend \$700 worth of stuff with the government so I can get my medications." (African-American female PLWH)

Providers noted that their female clients have had relatively few access problems with HIV medications. This sentiment was echoed among female focus group participants. However, both providers and consumers reported complex adherence issues. These include lack of trust in the medications (several focus group participants referred to antiretroviral therapy as “poison”), unstable housing and living situations, and mental health and chemical dependency barriers. Additionally, women of color and female immigrants may face cultural challenges interacting with the medical system. As a result, the gap between male and female PLWH has widened in the past two years regarding current medication status. Female survey respondents remain significantly less likely than males to be on antiviral medications (59% versus 82%), protease inhibitors (31% versus 57%) and drugs to treat or prevent opportunistic infections (27% versus 45%).

Providers of services to women noted that their clients are utilizing a wider array of services from across the Continuum of Care, including medical care. Nevertheless, based on responses to the 2001 consumer survey, female PLWH were slightly less likely to use several key services than male PLWH. Women were slightly less likely than men to use primary care (89% versus 95%), the Washington State AIDS Prescription Drug Program (42% versus 55%), and health insurance continuation programs (47% versus 59%). Women were also less likely than men to use case management (67% versus 81%), despite information from women in focus groups about the vital importance of case managers in helping them access needed services. Women were equally as likely as men to use mental health therapy (47% versus 48%). Although women were no more likely than men to report using injection and/or other street drugs, they were significantly more likely than men to report receiving substance use counseling (25% versus 15%).

3. Service Priorities

Female survey respondents ranked housing assistance and related services as their number one service priority (Table 37). Client advocacy tied with case management as the second most-frequently mentioned priority, followed by primary medical care, counseling (emotional support) and dental care.

Reversing a trend observed in 1997 and 1999, female and male PLWH reported several significant differences in service prioritization. Women were significantly more likely than men to prioritize housing services (60% versus 45%), client advocacy (particularly peer advocacy) (50% versus 33%), and counseling (emotional support) (40% versus 26%). Conversely, women were significantly less likely than men to prioritize clinical services, such as medical care (43% versus 67%), dental care (39% versus 58%) and drug prescription programs (29% versus 41%).

Table 37. Service Priorities: Women (n=72; 3 missing responses)

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Housing assistance/related services	43	60%
2 (tie)	Client advocacy	36	50%
2 (tie)	Case management	36	50%
4	Ambulatory/outpatient medical care	31	43%
5	Counseling (emotional support)	29	40%

6	Dental care	28	39%
7 (tie)	Direct emergency financial assistance	26	36%
7 (tie)	Insurance programs	26	36%
9	Food/meals	23	32%
10	Drug prescription program	21	29%

As noted by providers, the population of women with HIV is geographically more dispersed than males, and less likely to reside close to the core of services located in central Seattle. As a result, women exhibit greater transportation needs in order to access most services. Female PLWH rated peer emotional support significantly higher than males, based largely on reported feelings of isolation and lack of information about available services. Focus group participants and providers themselves noted that peer support services are vital for women not only for the emotional support they receive, but for the provision of informal access linkages to treatment information, medical care and social services.

4. Service Gaps

Female survey respondents were similar to other populations in their ranking of service gaps. Women ranked direct emergency financial assistance, housing assistance and related services, client advocacy (particularly access to medical information specific to women's health issues), food/meals and alternative, non-Western therapies among their top five service gaps (Table 38).

In comparison to previous surveys, differences in service access based on gender were reported in very few service categories. However, 32% of female respondents noted difficulty in accessing emergency financial assistance, as compared to 22% of males. Women were also more likely than men to identify gaps in housing assistance and related services (25% versus 18%) and in food and meal programs (21% versus 8%).

“Even with all the services that are available now, I find I can’t manage on my monthly SSDI check. Making the transition back to work is stressful and I need more support and services to get me back on my feet again. It’s hard to socialize and interact when you’re not even financially breaking even.” (White female PLWH)

Table 38. Service Gaps: Women (n=75)

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Direct emergency financial assistance	24	32%
2	Housing assistance/related services	19	25%
3	Client advocacy	18	24%
4 (tie)	Food/meals	16	21%
4 (tie)	Alternative/non-Western therapies	16	21%
6	Counseling (emotional support)	14	19%
7	Dental care	10	13%
8 (tie)	Case management	9	12%

8 (tie)	Mental health therapy/counseling	9	12%
10	Legal assistance	8	11%

One key finding on the 2001 survey was that women of color exhibited greater access gaps than white female PLWH in almost all service categories. Female PLWH of color were almost three times as likely as white females to identify gaps in access to case management (17% versus 6%), noting that very few case managers of color were available in the Continuum to assist them. Women of color were also more likely than white women to identify gaps in housing assistance (29% versus 19%), legal assistance (14% versus 6%), dental care (17% versus 10%), food/meals (31% versus 10%), and peer counseling/emotional support (24% versus 13%). Latinas, in particular, were more likely to identify service gaps, based largely on language barriers and concerns about confidentiality.

Providers were in agreement regarding the gap in financial services available to women. In particular, providers noted that funds seem to be diminishing to assist their clients in paying rent and utilities and managing transportation expenses. The processes by which clients access these funds also continue to become more restrictive and complex than in past years, making it difficult for women to negotiate the various systems that administer financial assistance programs.

Other services which providers identified as gaps for their female clients include housing, transportation and child care. Providers expressed ongoing concerns that there are few housing options for women with dependent children, and that available options are often located far from core medical services.

Very few female survey respondents reported a gap in primary care access (only 3 out of 75 female PLWH stated that they needed, but could not get medical care). However, providers noted that utilization of medical services, not access to these services, is the challenge for their clients. Reasons for this situation are outlined below, under “Access Barriers.”

5. Access Barriers

On the 2001 consumer survey, female consumers identified lack of information as the key access barrier to services (Table 39). Women in focus groups also noted that, prior to accessing HIV-related medical care and case management, they were relatively unaware of services within the HIV system. Many stated that it was only through meeting other women living with HIV that they developed any sense of knowledge about the spectrum of services at their disposal. As noted by one service provider, “Women are a ‘population,’ not a community.” This is particularly true when compared to gay/bisexual men who have a built-in community to service their support and information needs. As a result, peer advocacy and support groups assume a vital role in service access for female PLWH.

Table 39. Access Barriers: Women (n=75)

BARRIER	# OF VOTES	% OF RESP.
Lack of information	22	29%
Financial (can't afford)	12	16%
Geography (live too far away)	6	8%
Conflicts with schedule	6	8%
Haven't asked	5	7%
Waiting list/availability	5	7%

“We have so many different needs. It seems as if the whole of HIV has been based around the male person. From the amount of medicine the doctors consider therapeutic to the kinds of services available. What’s up? Can we start making it more woman and family friendly?” (American Indian female PLWH)

Providers of services to women noted that histories of mental illness and chemical dependency are major barriers to their clients’ ability to access services, and that many of the consumers they see come from abusive families and/or partner situations. Several providers pointed to general “life chaos” for their female clients, describing the complex issues surrounding poverty, parenthood, lack of education, and lack of social support, all of which make attention to personal health care more difficult.

It should also be noted that, as in previous years, female consumers and providers alike reiterated that women often defer to the needs of family members rather than accessing care themselves. Given the high percentage of female survey respondents who report having dependent children (37%), it is likely that many of the HIV+ women who are not receiving medical care have refrained from accessing care due to family obligations. Improvements in child care access, transportation for families, and housing options for families may be necessary to help these women obtain and maintain primary care.

Several focus group participants noted concerns about confidentiality as a barrier to their trust in receiving services. They may feel the need to hide their diagnoses from co-workers, family members (especially children) and their traditional support systems (e.g., church communities, school groups, etc.). In general, consumers reported feeling more social stigma about their HIV status than men.

Despite these access barriers, focus group participants did note unanimously that the service system for women has improved dramatically over the past decade. As one participant noted, “I get into the system easier than guys.” As more and more services have been developed that focus specifically on women’s needs, the key issue appears to be integrating women initially into the system and maintaining their engagement, rather than a lack of available services. Providers and consumers offered the following suggestions about how to improve service delivery and access for women living with HIV/AIDS:

- Develop increased flexibility around appointments, both in terms of time and location. Due to family and other time demands, women are not always able to come to their appointments when they are scheduled. If a client arrives late, try to ensure that she can still keep her appointment, if at all possible.
- Address the increasing demand for affordable housing for families. Explore ways to increase housing options for women with HIV who have dependent children.
- Provide accessible and available transportation for women and their families, not only to medical appointments, but to other important services.
- Expand access to childcare services. This includes both onsite care available at clinics and agencies, but off-site child care resources that are responsive to emergent needs.
- Acknowledge the intrinsic and ever-growing relationship between domestic violence and HIV status. Providers report that many of their female clients come from histories or current situations of domestic violence. However, most domestic violence agencies are ill-equipped to deal with HIV-related issues and HIV providers are frequently uneducated on domestic violence and its consequences. Linkages and cross-trainings between these systems are vital.
- Develop awareness among the service provider community of cultural issues as they specifically relate to female PLWH. This extends beyond simple language differences, to include understanding about family dynamics, education, the role of women in various cultures and the ways in which women of various backgrounds understand and access the medical system.

E. East and South King County Residents

“People in South County are scared. You don’t want to walk around talking about the fact that you’ve got AIDS. Most of the people I’ve talked to live down here to get away from the city. For some people, it’s actually physically painful to ride the bus. Having just one little satellite thing down here which had a clinic and support group-type thing would be great.”
(Male PLWH, South King County)

1. Epidemiologic Profile

Of the 6,096 cumulative King County AIDS cases reported through the end of 2000, 82% were diagnosed in Seattle, 16% were living in other areas of the county and 2% had no known zip code at time of diagnosis (Table 40). Of the non-Seattle cases, 61% were residents of South King County, 37% were from the Eastside and 2% from Vashon Island.

Table 40. Demographic characteristics by residence of cumulative King County AIDS cases through 12/00

	City of Seattle		KC, Outside Seattle		Unknown	
	Number	%	Number	%	Number	%
SEX						
Male	4,793	(96)	902	(90)	108	(94)
Female	191	(4)	95	(10)	7	(6)
RACE/ETHNICITY						
White	3,999	(80)	788	(79)	95	(83)
Black	509	(10)	112	(11)	11	(10)
Latino/Latina	298	(6)	69	(7)	7	(6)
Asian/Pacific Islander	96	(2)	19	(2)	2	(2)
Am. Indian/AK Native	82	(2)	9	(1)	0	(0)
EXPOSURE						
Male/male sex	3,862	(77)	662	(66)	76	(66)
Injection drug use (IDU)	264	(5)	75	(8)	7	(6)
IDU & male/male sex	538	(11)	74	(7)	11	(10)
Heterosexual contact	116	(2)	69	(7)	9	(8)
Undetermined/Other	204	(4)	117	(12)	12	(10)
TOTAL CASES	4,984	(82)	997	(16)	115	(2)

Since named HIV reporting began in King County in 9/99, 220 people with non-AIDS HIV infection have been newly diagnosed. Of these, 76% were residents of Seattle, 21% lived outside of Seattle and 2% had an unknown residence at time of diagnosis. These HIV cases represent persons with more recent diagnoses compared with AIDS case report data and suggest that the proportion of new HIV infections is increasing outside of Seattle.

Compared to Seattle residents reported with AIDS, those living in other areas of King County were more likely to be female (10% versus 4%) and to have been reported as infected with HIV either heterosexually (7% versus 2%) or through non-MSM injection drug use (8% versus 5%).

2. Service Trends

As in previous years, East and South King County providers reported that a large majority of their clients were white and self-identified as gay. Despite the fact the non-Seattle PLWH are more likely to be female, providers noted that the number of female PLWH on their caseloads continues to decrease, as more female clients living outside Seattle prefer to receive services from Seattle-based providers and agencies. This discrepancy was noticeable among female focus group participants, many of whom reside outside of Seattle, but receive services in the city.

Reversing a trend from previous years, non-Seattle providers reported that they have seen fewer PLWH of color in the past two years. Although South County providers noted a small increase in the number of Latinos on their caseloads, all non-Seattle providers noted seeing fewer African-Americans and PLWH of other races. They attribute this to reasons similar to the decrease in female clients, as clients of color have become more familiar with Seattle-based services and are willing to travel to the city for their care and ancillary support.

Another change from recent years is the increase in self-identified gay and bisexual men receiving services in South and East King County. In prior years, providers reported seeing many clients who denied MSM transmission, or who were not “out” about their sexual orientation and behaviors to their family or community. Although this continues to be an issue for many non-Seattle PLWH, the numbers seem to be decreasing.

Non-Seattle consumers represent a diverse socioeconomic range, although East Side providers noted a higher proportion of their clientele who are earning over \$40,000 than was reported by Seattle or South King County providers. South County clients are primarily middle to lower middle class. In both sub-populations, many consumers are now living at or below the poverty level due to AIDS-related disability. For those who are not yet disabled, many are caught in a double bind: their incomes are insufficient to cover the services they need, but exceed Medicaid and/or Ryan White income eligibility limits.

“I would love to see an occasional potluck for people with HIV/AIDS. A place where we could meet each other. It’s very frustrating living on the Eastside, and having case managers change hands. It seems I just have a rapport with one and someone else is put in charge. The only reason I don’t quit is that I need the services, which outweighs the frustration.” (MSM PLWH, East King County)

As noted previously, East and South King County providers report that most of their clients travel to Seattle to access non-medical services. For many services, such as emotional support, mental health counseling, and dental care, there may be few, if any, options available to non-Seattle PLWH in their place of residence. Because East and South King County consumers may not be “out” about their HIV status to others in their communities, consumers may not access support services in their place of residence for fear of being identified as living with HIV/AIDS.

In general, providers report that clients’ health has fluctuated in the past few years. Providers have seen an increase in clients with symptomatic HIV infection, and more deaths than in recent years. In prior surveys, significantly higher percentages of East and South County respondents reported living with HIV, non-AIDS than Seattle residents. However, the percent of consumers who reported AIDS diagnoses were almost equal for all geographic areas: East County (51% of consumers reported receiving an AIDS diagnosis), South County (53%) and Seattle (53%).

Providers report that East and South King County PLWH have good access to prescription medications. Providers estimate that a large majority of their clients are adherent to drug regimens, although South County providers noted that clients require a greater degree of medication management than East County PLWH. South County survey respondents reported higher levels of adherence problems (37% reporting difficulty in taking medications as prescribed) than did Seattle residents (31%) or PLWH in East County (23%).

East and South King County survey respondents were also significantly less likely than Seattle residents to report co-morbidities. Thirty-four percent of Seattle respondents reported being diagnosed with some form of mental illness, versus 25% of South KC respondents and only 12% of East KC respondents. However, providers of services to non-Seattle PLWH noted that over half the clients on their caseload have mental health issues, either diagnosed or undiagnosed, with many suffering from clinical depression. They noted that their clients are not accessing mental health services despite their suggestions and referrals.

Non-Seattle survey respondents reported comparable levels of substance use as Seattle residents. This contradicts epidemiologic data that suggests higher levels of non-MSM IDU-related HIV transmission among non-Seattle PLWH. Providers noted that substance use among their East and South County clients is more likely to be hidden than among Seattle clients, because the population of active drug users is smaller and more clandestine than in the city.

In prior years, a significantly lower percentage of South and East King County consumers reported currently accessing primary care than did Seattle residents (84% versus 94%, on the 1999 consumer survey). Although non-Seattle survey respondents in 2001 reported higher rates of primary care utilization rates than in previous years, the percentage is still lower than that for Seattle consumers (91% versus 96%). Non-Seattle consumers were no more likely than Seattle residents to report being unable to obtain medical care (only 1% of each population stated that they could not access needed medical care). Based on information from South and East King County focus group participants and from provider interviews, it appears that non-Seattle residents may be less likely to actively pursue ongoing medical monitoring, unless symptoms or medication side effects are present. This may be related to fears about confidentiality and disclosure (having to take time off from work and/or explain to friends/colleagues about attending medical appointments) as well as geographic barriers such as traveling into Seattle to attend appointments.

In past years, South and East KC PLWH reported significantly lower utilization rates in several other Ryan White service categories than their Seattle counterparts. However, due to recent Planning Council-applied funding caveats, and increased outreach activities by Seattle-based HIV service agencies, these disparities have lessened to a great degree in 2001. South and East King County PLWH exhibit greater or similar utilization rates to Seattle residents in many key service areas: insurance continuation programs (used by 64% of non-Seattle clients versus 55% of Seattle PLWH), AIDS drug assistance program (56% versus 52%), client advocacy, including information about HIV disease and therapies (86% versus 83%), case management (77% versus 80%), and dental care (68% versus 72%).

The sole service areas in which South and East King County PLWH survey respondents reported lower utilization rates were mental health therapy and counseling (39% versus 51%) and substance use treatment and counseling (5% versus 19%). This is consistent with survey responses that suggest that non-Seattle consumers are less likely to have been diagnosed with mental illness and less likely to have histories of substance use. Surprisingly, non-Seattle residents were no more likely than Seattle residents to use transportation services (32% each). Several focus group respondents noted that they continue to drive to Seattle for appointments even when they are feeling ill or weak, rather than rely on public or volunteer transportation assistance.

3. Service Priorities

East and South King County survey respondents identified service priorities which were fairly similar to the responses of the survey population as a whole (Table 41). Dental care emerged as the number one ranked priority, followed by primary medical care, insurance programs, case management and housing assistance and related services.

As in previous years, focus group participants highlighted case management as a vital service. This was particularly true of South County consumers, who noted that their case manager served as their primary link to care and support services. East County PLWH were somewhat less likely to prioritize case management services. Consumers who participated in the East County focus group had been living with HIV for quite a while, and felt more confident navigating the Continuum of Care themselves.

**Table 41. Service Priorities: East and South County Residents
(n=98; 9 missing responses)**

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Dental care	65	66%
2	Ambulatory/outpatient medical care	57	58%
3	Insurance programs	51	52%
4 (tie)	Case management	41	42%
4 (tie)	Housing assistance/related services	41	42%
6	Drug prescription program (ADAP)	40	41%
7	Client advocacy	39	40%
8	Direct emergency financial assistance	29	30%
9 (tie)	Food/meals	27	28%
9 (tie)	Counseling (emotional support)	27	28%

As previously noted, place of residence did not appear to play a major factor in the ways in which consumers prioritized most services. This is particularly true for South County consumers, whose priority rankings and percentage response mirrored Seattle PLWH in almost all cases. However, East County PLWH were significantly more likely than Seattle or South County consumers to prioritize referral programs (29% versus 8% and 9%, respectively) and

alternative, non-Western therapies (39% versus 31% and 10%, respectively). East County consumers were also significantly less likely than other PLWH to prioritize primary medical care (46% versus 64% of Seattle PLWH and 63% of South County PLWH).

4. Service Gaps

East and South King County survey respondents reported similar service gaps as other PLWH populations. The top five service gaps identified by non-Seattle consumers included direct emergency financial assistance, alternative therapies, counseling (emotional support), client advocacy and housing assistance (Table 42). With the exception of housing assistance, the four top ranked service gaps for 2001 are identical to those identified by East and South KC PLWH in 1999.

Table 42. Service Gaps: East and South County Residents (n=107)

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Direct emergency financial assistance	31	29%
2	Alternative, non-Western therapies	28	26%
3	Counseling (emotional support)	25	23%
4	Client advocacy	24	22%
5	Housing assistance/related services	18	17%
6	Food/meals	15	14%
7	Dental care	14	13%
8	Legal assistance	13	10%
9	Mental health therapy/counseling	11	9%
10	Referral	10	8%

South King County clients expressed dissatisfaction with the quality of service provided through DSHS. Several of them described lengthy waiting times for services, lack of professionalism on the part of providers and failure to be given explanations as to why benefits were delayed or denied. Participants were also concerned about tighter eligibility requirements being placed on emergency grants from Lifelong AIDS Alliance, but acknowledged that the reasons for these restrictions were valid.

Service gaps in alternative therapies, peer counseling/emotional support and dental care were each related to the scarcity of available programs outside of central Seattle. Both of the major HIV-related alternative care providers are located in Seattle. Although one provider has begun to sub-contract for naturopathy and acupuncture through East and South County clinics, none of the focus group participants were aware that this option existed. Group support programs are also offered almost exclusively in Seattle, and peer one-on-one support options are limited based on volunteer availability in outlying areas of the county. It should be noted, however, that attempts to offer HIV-focused support groups outside of Seattle have met with minimal attendance, due in part to client concerns about anonymity and confidentiality in their home communities. Focus group participants also noted that while dental care is available throughout the county, there

continues to be a shortage of dental providers outside of Seattle who are knowledgeable about HIV/AIDS dental manifestations and/or willing to accept medical coupons.

“I have three options: I can drive myself, which isn’t good because of parking and my car is usually falling to pieces. The second option is to take the bus, which isn’t always wonderful when you are going to the doctor and it also requires three buses and lots of logistics planning. The third option, which is no longer works very well, was [volunteer] transportation services. There are a lot of volunteers on the other side of the lake, but it is hard to get volunteers on this side. The last time, it was just a bad experience.” (Male PLWH, East King County)

Focus group participants also expressed dissatisfaction with the availability of ancillary support services, such as food/meal programs, transportation and volunteer home chore. Consumers pointed to a lack of available volunteers to provide these services, which they attributed to disinterest among non-Seattle residents rather than to agency inaction in recruitment. While most of the focus group participants own cars and drive themselves to appointments, they acknowledged that transportation can be problematic when they are not feeling well. Bus service outside of Seattle is infrequent except during business hours and the routes are often lengthy and time-consuming.

Comparisons between gaps identified by East and South County consumers in 2001 and those identified in 1999 reveal that gaps in most categories have decreased. In particular, the gap identified in alternative, non-Western therapies has dropped from 41% of non-Seattle PWLH to 26% and the gap in financial assistance has decreased from 39% to 29%. Although these figures suggest that several needed services are not as available to non-Seattle PLWH as would be optimal, recent efforts to overcome these discrepancies seem to have been somewhat successful.

5. Access Barriers

As with other consumer sub-populations, East and South King County consumer survey respondents identified a lack of information about available services and an inability to afford needed services as their main access barriers (Table 43). As previously noted, financial barriers were especially pressing for consumers whose income and/or assets did not qualify them for Ryan White-funded services or other government programs, but who could not afford out-of-pocket service fees. Information about HIV-related services is not as readily accessible outside of central Seattle, where the large majority of service agencies are located. As a result, consumers can become highly dependent on case managers to help them learn of and access services when needed.

“I do wish there could be emergency money to keep auto bills paid, for independence. Living in South King County, there’s nothing in the way of support groups or heterosexual contact groups between Seattle and Tacoma.” (Female PLWH, South King County)

Table 43. Access Barriers: East and South County Residents (n=107)

BARRIER	# OF VOTES	% OF RESP.
Lack of information	34	32%

Financial (can't afford it)	18	17%
Geography (live too far away)	12	11%
Service doesn't exist/not available	9	8%
Eligibility (based on financial status)	6	6%

Based on provider interview and consumer focus group response from the 2001 needs assessment, it appears that geographic isolation and lack of non-medical services in non-Seattle King County continue to serve as barriers to service access for this population. PLWH in South and East King County often have to travel long distances to access care in Seattle, prompting some consumers to forego ongoing medical monitoring of their HIV until such time as they are clinically ill.

When asked to comment on ways in which the service system can become more responsive to non-Seattle PLWH, providers suggested that change will not be easy. As several providers noted, many of their clients have chosen to live in South and East County precisely to be apart from the urban Seattle experience. Because the outlying areas of the county are not as densely populated, they will never be as service-enriched as Seattle. They noted that until East and South King County municipalities begin to embrace HIV issues as their issues significant change will not occur.

Providers and consumers offered the following suggestions for overcoming access barriers for East and South King County PLWH:

- Improve coordination and communication between Seattle-based providers and providers of services to non-Seattle residents. This includes outreach to primary care providers, dentists, mental health providers, and other social service agencies in East and South County.
- Increase overall community education and awareness regarding HIV/AIDS issues. Target educational and outreach programs to schools, churches and social service organizations.
- Decrease client isolation through the development of informal support services and client networks outside of Seattle. Use satellite social service centers as the focus of client support and services.
- Maintain and/or expand case management presence in South and East Counties. In these geographic areas, the case manager serves as both a liaison and outreach specialist between the Continuum of Care and social and health service providers in the rest of the county.
- Acknowledge the shortcomings of county-wide public transit programs for persons with AIDS and other disabilities. Assign priority status to the development of new transportation initiatives, both public and volunteer, which can address these issues.

F. Homeless Persons

“Please remember that all of us who have HIV were once tax-paying, voting, working persons. It’s only by the grace of God that this isn’t you.” (Homeless female PLWH)

1. Epidemiologic Profile

Although there have been no local population-based surveys of HIV infection in the homeless population in King County, studies indicate that homeless men and women are at high risk for HIV. Homeless people reported with AIDS in King County were more likely to be persons of color and to have been exposed through injection drug use compared to those who were not homeless.

Status and trends in AIDS cases: In King County AIDS case statistics, “homeless” is defined as having no resident zip code at time of AIDS diagnosis. This definition may undercount the number of homeless AIDS cases if, for example, the zip code of a shelter or friend’s home is reported as the zip code of residence, or if the client becomes homeless following diagnosis. Eighty-eight (2%) of the 4,448 AIDS cases diagnosed in King County between January 1991 and December 2000 were reported as homeless at time of diagnosis. During this time frame, 59% of homeless persons diagnosed with AIDS were people of color and 63% were either IDUs or MSM/IDUs, compared to 21% and 16% respectively among persons who were not reported as homeless (Table 44).

Table 44. Demographic characteristics by homeless status of cumulative King County AIDS cases through 12/00

	Homeless at time of diagnosis		Not Homeless at time of diagnosis	
	Number	%	Number	%
SEX				
Male	79	(90)	4,202	(94)
Female	9	(10)	246	(6)
RACE/ETHNICITY				
White	36	(41)	3,494	(79)
Black	34	(39)	484	(11)
Latino/Latina	11	(13)	304	(7)
Asian/Pacific Islander	0	(0)	95	(2)
Am. Indian/AK Native	7	(8)	71	(2)
EXPOSURE				
Male/male sex	25	(28)	3,311	(74)
Injection drug use (IDU)	32	(36)	262	(6)
IDU & male/male sex	24	(27)	428	(10)
Heterosexual contact	1	(1)	173	(4)
Undetermined/Other	6	(7)	255	(6)
TOTAL CASES	88	(2)	4,448	(98)

Population size: The McKinney Act (Public Health Law 100-628, November 7, 1988) defines homelessness as: “A homeless person is an individual who lacks a fixed, regular, and adequate residence or an individual who has a primary night-time residence that is either (a) a supervised or publicly operated shelter designed to provide temporary or transitional living accommodation or (b) a public or private place not designed for, or ordinarily used as, a regular sleeping accommodation for human beings.” Approximately 5,000 persons are homeless in King County

on any day, of which 500-2,000 are youth/young adults. An estimated 25,000 persons have experienced homelessness in the past year.

HIV seroprevalence: In HIV prevalence surveys conducted by the Centers for Disease Control and Prevention between 1989-1992 of health clinics serving the homeless in ten different cities, the median seroprevalence was 3.3%. In 1998, AIDS Housing of Washington analyzed the results of more than 5,650 surveys of PLWH conducted in twelve regions around the country between 1994-1998. Seven percent of all respondents reported that they were living on the streets, in a shelter, or in a residential hotel/motel at the time they completed the survey, and 41% of respondents had been homeless at some point in time.

2. Service Trends

(NOTE: Due to difficulty in obtaining survey responses from consumers who were currently without a residence, the needs assessment survey asked consumers if they were currently homeless (without a permanent residence) or had been homeless during the past twelve months. In this manner, it was anticipated that the survey would capture data from individuals for whom homelessness was a historical, as well as current, problem. Of the 538 survey respondents, 58 (11%) reported homelessness within the past year.)

Consistent with the 1999 needs assessment, providers of services to homeless adults with HIV reported that their client caseloads are largely male, although increasing numbers of homeless female PLWH have been observed in the past two years. On the 2001 consumer survey, homeless respondents were twice as likely than non-homeless respondents to be female (26% versus 13%).

Providers noted that it was very difficult to determine the mode of HIV transmission for many of their homeless clients, due to multiple sexual and substance use risk factors. MSM sexual activity continues to be fairly common among the men, although many do not identify as gay or bisexual. This is particularly true for the growing number of African-American homeless PLWH. Trading of sex for money, drugs or shelter contributes to high-risk behaviors among both men and women in this population. Homeless survey respondents were over three times more likely than non-homeless respondents to report IDU or MSM/IDU history (35% versus 10%).

Consistent with epidemiological trends, over half of the homeless clients that providers reported seeing are persons of color. This includes increasing numbers during the past two years from all non-Caucasian populations. Persons of color were also over-represented among the consumer survey population, with 26% of homeless respondents being African-American, 19% Latino/ Latina, 7% American Indian and 3% Asian/Pacific Islander. Only 41% of the homeless survey respondents identified as Caucasian, as opposed to 74% of non-homeless respondents. As first observed in 1995, providers continue to see increasing numbers of homeless clients who are new to King County. The large majority of these new arrivals are English speakers, but providers did note a slight increase in the number of Spanish speaking homeless PLWH who are now seeking services. Providers also noted that they are seeing an increase in homeless clients who have re-located from downtown Seattle to other points outside the central core of Seattle.

Multi-drug use is also increasing among homeless PLWH, with some providers estimating that as many as 80% of their homeless clients are current or former substance users. Respondents to the consumer survey who stated that they had experienced homelessness during the past year were almost four times more likely than other consumers to report histories of injection

drug use (22% versus 6%). Most clients are alcohol abusers, with increasing numbers of homeless PLWH reporting heroin, crystal meth, and cocaine use.

Although providers noted that their clients are more willing to enter treatment than in the past, access to treatment remains difficult due to long waiting lists, complicated assessment processes, increased paperwork, and fewer detox beds. For most clients, adherence to substance use treatment goes hand-in-hand with housing stability. If the client is released from in-patient treatment back to the streets, the odds of relapse increase dramatically.

Mental illness diagnoses have historically been high among this population and continue to increase. Providers noted that the majority of their clients have been diagnosed with clinical depression. They also report an increase in the clients they are seeing who have Axis II conditions (personality disorders), as well as large numbers of clients with Axis I diagnoses (bipolar disorder, schizophrenia or organic disorders). Homeless survey respondents were significantly more likely than other PLWH to report having been diagnosed with a mental illness (43% versus 29%). As with substance use treatment, providers noted a connection between housing and mental health status. In many cases, the clients' mental illness remains undiagnosed until successful housing is secured.

Many homeless PLWH also have histories of incarceration. Providers report that over half of their homeless clients have spent some time in jail or prison, with most crimes being drug related. The number of clients who are entering the HIV/AIDS care system immediately upon release from jail is increasing. Survey respondents who reported being homeless were significantly more likely than other consumers to report having been in jail or prison during the previous year (22% versus 5%).

Providers reported seeing homeless clients across the entire spectrum of HIV disease. Some of the homeless clients they first encounter have been HIV+ for a long while and have received no care for their illness. Many of these individuals have high viral loads and low T-cell counts, and first present when their illness is fairly advanced. Homeless survey respondents were significantly more likely than other PLWH to be HIV+ non-AIDS, (62% versus 34%), and less likely to have been AIDS diagnosed. However, the number of homeless PLWH who are now receiving AIDS diagnoses is increasing, according to providers.

Homeless PLWH are slightly less likely than other PLWH to be using antiviral medications, protease inhibitors and medications to treat or prevent opportunistic infection. However, homeless PLWH were significantly more likely to report having adherence problems related to their medical regimens (41% to 29%). Providers noted that access to prescription drugs is not a major problem for their clients, but other lifestyle factors (e.g., substance use, mental illness) make adherence to HAART therapy extremely difficult. As a result, doctors and their homeless PLWH clients may often agree not to begin HAART therapy until some level of housing stability has been established.

Although 91% of homeless PLWH respondents to the consumer survey reported currently receiving primary care for their HIV infection, this is probably an overestimate based on targeted sampling of homeless persons currently in the care system. It is probable that many homeless PLWH who are HIV infected are unaware of their serostatus, and are not currently receiving primary care or other support services.

Once homeless PLWH become connected to the care service system, either through the efforts of outreach case managers or placement in transitional or permanent housing,

service utilization rates are comparable to non-homeless PLWH. In fact, 2001 homeless survey respondents reported service utilization rates that were fairly similar to those of non-homeless PLWH. In several categories, homeless respondents reported higher rates of utilization, such as food and meals (60% versus 46%) and transportation services (41% versus 31%), while in other key service areas homeless PLWH reported lower utilization rates: dental care (62% versus 72%) and client advocacy (72% versus 85%).

3. Service Priorities

Consumer survey respondents who reported themselves as currently homeless (or homeless within the past year) listed housing assistance and housing related services as their highest priority (Table 45). Other services that were ranked among the top five highest priorities were case management, dental care, primary medical care and emergency financial assistance.

Homeless consumers were significantly more likely to prioritize housing assistance than other PLWH (69% versus 45%). The need for affordable, safe housing programs is obviously a high priority for most homeless individuals, particularly for homeless men and women living with HIV. Participants in the homeless PLWH focus group expressed concern that living in shelter situations as a person with HIV is extremely difficult. They relayed experiences of being ostracized by other shelter residents, victimization and violence, and lack of privacy and confidentiality in taking medications. Several consumers also spoke of overt discrimination they experienced at the hands of shelter staff who did not want HIV+ individuals in their facilities. However, for persons who have not lived in stable housing situations for a long period of time, the transition into permanent housing can be difficult without readily accessible support services. Providers emphasized the need to develop housing services that provide on-site access to substance use treatment, mental health counseling, and medication management.

“When I came to this clinic, I had only been here for four days in this city. And I told my case manager my situation, that I’d been homeless and how sick I was getting at the shelter because of all the different things coming through there. He gave me a number to a hotel that’s like a program. And he did really great for the housing.” (Homeless female PLWH)

Both consumers and providers of services to homeless PLWH stressed the importance of case management. Because many homeless PLWH enter the HIV/AIDS care system with little or no knowledge of available services, dependence on case managers for information, referrals and assistance with service access is quite high. Providers noted that case management has become increasingly important in helping their homeless clients with medication adherence issues. Several participants in the homeless focus group expressed deep gratitude for the ongoing support and assistance provided by their case managers, but noted that case managers seem to be busier and more overworked than in previous years.

**Table 45. Service Priorities: Homeless Persons (Current or in past year)
(n=55; 3 missing responses)**

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Housing assistance/related services	38	69%
2	Case management	30	55%
3	Dental care	29	53%

4	Ambulatory/outpatient medical care	26	47%
5	Direct emergency financial assistance	23	42%
6	Food/meals	22	40%
7	Client advocacy	21	38%
8	Insurance programs	18	33%
9	Mental health therapy/counseling	16	29%
10	Substance use treatment/counseling	15	27%

As in previous years, providers of services to homeless PLWH highlighted the importance of substance use treatment as a top priority for their homeless clients. An increasing percentage of homeless consumers are in agreement with this opinion, as the rate of homeless PLWH who prioritized substance use treatment rose from 17% in 1999 to 27% in 2001.

Consumer focus group participants reported that medical care was very easy for them to access, once they decided to seek care. They noted that information about HIV medical care was available to them through homeless programs and through word of mouth among other homeless PLWH. Several consumers stated that “the word on the street” is that private doctors will treat you badly if they perceive you to be substance-using, but their experiences with public clinics proved otherwise. Homeless consumers expressed high levels of satisfaction with the care they had received, particularly in comparison to medical care many of them had received prior to moving to King County.

4. Service Gaps

Current or formerly homeless consumers ranked housing assistance and related services as the service they most frequently needed but could not obtain (Table 46). Housing services were followed by alternative therapies, emergency financial assistance, client advocacy and peer emotional support programs.

Unlike prior years, homeless PLWH survey respondents identified relatively similar service gaps as other consumers. The sole disparities were observed in the areas of housing assistance (40% of homeless PLWH noting difficulties accessing the service versus 17% of other PLWH), client advocacy (29% versus 18%), and alternative/non-Western therapies (33% versus 21%).

**Table 46. Service Gaps: Homeless Persons (Current or in past year)
(n=58)**

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Housing assistance/related services	23	40%
2	Alternative, non-Western therapies	19	33%
3	Direct emergency financial assistance	18	31%
4	Client advocacy	17	29%
5	Counseling (emotional support)	15	26%
7 (tie)	Mental health therapy/counseling	10	17%
7 (tie)	Referral	10	17%
9 (tie)	Legal assistance	9	16%
9 (tie)	Dental care	9	16%
11 (tie)	Food/meals	7	12%
11 (tie)	Transportation	7	12%

“I plan to move to wherever I can afford to. I can’t afford to stay here in Seattle. I mean, it’s stupid of me to stay here and be homeless for years when I can move [to another part of Washington State] and have an apartment just like that. But what are my choices? Stay here? Stay homeless?” (Homeless female PLWH)

Lack of housing remains the greatest single barrier for homeless PLWH in their efforts to obtain or maintain continuity of HIV care and supportive services. The lack of permanent, safe housing compromises clients’ health due to unsanitary conditions, the threat of physical violence, and lack of privacy in dealing with personal health concerns. Transient living arrangements also complicate provider/client follow-up. These problems are exacerbated by the high rates of mental illness in the population.

Persons with criminal histories and/or current substance use issues face even greater challenges in obtaining housing. Focus group participants expressed a desire for “second chance” housing for persons with criminal records, particularly if the record is more than five years old. They

suggested that housing providers need to look at criminal records with time consideration (so as not to penalize people based on older convictions) as well as the severity of the offense

A further complication was noted by homeless focus group participants in 2001: the majority of the current HIV-specific housing units are located in downtown Seattle, the area of the EMA with the highest concentration of substance-using individuals and access to street drugs. Living in downtown Seattle may serve to subvert the efforts of homeless consumers who are striving to come to terms with their substance addictions. However, accepting housing choices in other parts of the county poses problems in accessing medical care and other needed services.

Unfortunately, the 2001 Report on HIV/AIDS Housing in Seattle-King County (prepared by AIDS Housing of Washington) suggests that King County continues to experience an affordable housing crisis. Although the number of available new housing units has increased by 13% from 1998 to 2000, the supply has not kept pace with the increasing need, resulting in increased demand by low and very low-income individuals and families with fixed or diminishing incomes. The situation is complicated for persons seeking HIV/AIDS housing, because average rents throughout most of the county exceed the fair market rents allowed by HUD (the federal Department of Housing and Urban Development). The estimated need for rental subsidies among people living with AIDS far exceeds federal HOPWA (Housing Opportunities for People with AIDS) funding for the entire EMA.

Until permanent or transitional housing can be provided, accessible food, nutrition and personal health care services are also necessary, but difficult to access. As in previous years, providers suggested combining meal programs with other social services, both as an incentive to attract clients and as a means to provide meals to persons in need. However, providers noted that the majority of homeless programs and shelters in King County are not capable of addressing the specific health care needs of their HIV infected clients.

Participants in the homeless PLWH focus group also reported a lack of peer advocacy and support programs. This is particularly true for homeless PLWH who have yet to connect with the HIV care system, and are not receiving medical care or do not have a case manager. They wanted to be able to share knowledge and information with other PLWH who have had similar experiences in safe, confidential settings. Several focus group members noted that it is very difficult – and dangerous – to mobilize against drug dealing and criminal behavior “on the street” or in residential settings for fear of violent reprisals.

5. Access Barriers

As with other consumer populations, homeless PLWH survey respondents identified lack of information about available services as the main barrier to accessing services in King County. (Table 47). This knowledge deficit is particularly problematic for clients who are recent arrivals to Seattle and those with severe mental health problems. As noted previously, access to effective case management becomes vital for these consumers in learning about the Continuum of Care and in helping them enroll in and follow through with services.

Focus group participants stated that homelessness itself is the greatest of all potential access barriers. Fulfilling basic needs, such as obtaining food, maintaining personal hygiene and

finding safe shelter, take precedence over medical and social service appointments. Both consumers and providers also noted that the perceived stigma attached to being homeless (or living in service-enriched housing) can also be a barrier for clients who seek other services.

Providers noted several ongoing barriers that impede homeless PLWH from obtaining housing. These include current and former substance abuse histories, mental illness, lack of housing or rental history and criminal records. In some cases, clients may minimize their substance use history or fail to disclose their current substance use in order to receive services. For those who are actively using, drug-seeking can become the “job for the day”, as noted by one focus group participant, and medical and social service appointments may be ignored. Even for those clients who do acknowledge readiness to enter treatment, availability of in-patient detoxification beds continues to be limited and waiting lists continue to be lengthy.

“We became homeless this year because we could no longer work and we had a very expensive house payment. It was nice. We were used to living that way. And we could have gotten housing real quick separately. They would have paid up to \$800 a month separately to house us. But it’s really hard to convince them to pay \$900 a month for us to live together. Now isn’t that stupid? It seems there is a glitch in the rules somewhere.” (Homeless gay male PLWH with partner)

**Table 47. Access Barriers: Homeless Persons (Current or in past year)
(n=58)**

BARRIER	# OF VOTES	% OF RESP.
Lack of information	20	34%
Financial (can’t afford it)	10	17%
Waiting list; not enough services	6	10%
Geography (live too far away)	5	9%
Service doesn’t exist; not available	3	5%

The ability of many homeless persons to cope effectively with HIV is further compromised by mental illness. This can complicate care at all levels: initial access, follow-through with appointments and ongoing treatment compliance. Skilled mental health professionals are vital in working with this population, particularly as the number of homeless clients who present with severe mental illness continues to grow.

Providers noted that lack of transportation, especially to medical appointments, is increasingly an access barrier for their homeless clients. This reflects the movement of clients out of the downtown core to other Seattle neighborhoods and the inherent transportation challenges associated with this.

Service providers and homeless consumers suggested several solutions for overcoming access barriers. These include:

- Educate the HIV/AIDS provider community about the realities of homelessness and mental health issues. Ensure that HIV service agencies feel welcoming to clients who are currently homeless or living in service-enriched facilities for formerly homeless persons.
- Educate the mental health, substance use and shelter provider systems about HIV issues. Work on developing increased sensitivity among these providers to HIV issues and increased capacity to make appropriate referrals into the HIV system.
- Expand the system of outreach to homeless individuals to improve case-finding and linkages to care services. In order for homeless persons to feel comfortable entering the HIV system (or any system), ongoing relationships must be developed and nurtured between outreach staff and clients.
- Improve collaboration and accountability between the HIV/AIDS, mental health, substance use treatment and housing systems. Although gains have been made in recent years, communication between these systems can still be difficult. Service providers in each system must take responsibility for optimal care of all clients, and not “hand off” homeless PLWH to providers in other arenas without ongoing follow-up and monitoring.
- Explore alternative housing options for persons with criminal histories. Although this population is extremely difficult to house, it may be possible to pilot transitional housing programs directed expressly to formerly incarcerated persons to improve their chances of successful permanent housing placement.

G. Youth and Young Adults (Ages 14-24)

“When I got tested, I didn’t get the results for a year due to thinking they would be positive. I lived in denial until I figured out I was ready to accept the news. I had an “It figures” attitude as opposed to “Why me?” I really wanted the person giving me my results to be a friend. The person did the best she could, but it was just a doctor at the clinic.” (Young adult female PLWH)

1. Epidemiologic Profile

HIV infection does not appear to be widespread among the general King County adolescent population, although it is present. Young men who have sex with other men (MSM) are disproportionately affected compared to other youth, and are at the greatest risk of HIV infection. Teenagers reported with HIV or AIDS through 12/00 are more likely to be African American and more likely to be female compared to older PLWH.

Status and trends in AIDS cases: From 1982 through December 2000, 6,096 AIDS cases were diagnosed in King County. Of these, 12 (<1%) were in persons 14-19 years old and 151 (2%) in persons between the ages of 20-24. As of December 2000, an additional 1,340 King County residents with non-AIDS HIV infection were diagnosed and reported. Of these, 43 (3%) were 14-19 and 170 (13%) fell between the ages of 20-24.

HIV seroprevalence: The estimated number of King County residents ages 14-19 with HIV is between 75 and 110 (midpoint=95). No estimates were available specific to the population of young adults between the ages of 20-24. Anonymous HIV prevalence surveys have been conducted in several specific populations in King County. Recent studies of HIV infection in youth and young adults reveal a variety of seroprevalence data (Table 48).

Table 48. Seroprevalence In Youth/Young Adults from Various King County Surveys

SOURCE OF DATA	AGE (YRS.)	HIV+/NO. TESTED	% HIV+
AIDS Prevention Program, 1996-2000	<20	27/1,122	2.4
AIDS Prevention Program, 1996-2000	20-24	282/4,413	6.4
STD Clinic, 1996-1999	<20	0/483	0.0
STD Clinic, 1996-1999	20-29	14/2,783	0.5
Young Men’s Survey, 1997-1998	15-18	0/85	0.0
Young Men’s Survey, 1997-1998	19-22	5/201	2.5
Young Men’s Survey, 1998-2000	23-29	22/462	4.7
Selected Drug Treatment Facilities, 1997-1999	<25	2/127	1.6

Important sub-group – Young gay males: Over two-thirds of the AIDS cases diagnosed between ages 13 and 24 were in males who had sex with other males (with or without injection drug use), 8% were non-MSM injection drug users, 9% had heterosexual risk, and 10% had no identified risk.

Results from risk behavior surveys provide important information about behaviors that may place young people at risk for HIV infection. Preliminary results from Public Health's Young Men's Survey show that 53% of MSM ages 15-18 and 64% of 19-22 year olds who had had anal sex in the past six months did not use a condom. The 1999 Seattle Public Schools Teen Health Risk Survey showed that 40% of high school students had had sex. Of those reporting sex in the previous three months, 61% had had sex without a condom at least once during that time.

2. Service Trends

Providers report that the demographic trends first observed among their adolescent clients in the late '90's continue: an increase in female clients, clients of color and increasing co-morbidity rates (chemical dependency and mental health issues). Providers now report that the majority of their young adult clients are female. Many of the young women have children, are pregnant, or are contemplating having children. This is consistent with data from the consumer survey that indicate that 68% of youth/young adult respondents are female, as opposed to 12% of respondents aged 25 and older.

Providers of services to youth/young adult PLWH describe their client population as predominantly unemployed, with most living at or below the poverty level. Young adult respondents on the consumer survey were significantly more likely than older consumers to report incomes under 100% of federal poverty level (58% versus 39%). Most of these young adult clients are receiving DSHS assistance. Many of the young PLWH are living in unstable living situations (on the street, in shelters, or in short-term arrangements with friends). The population of street-identified youth includes a high percentage of transient adolescents, who have little or no employment history and may not be integrated into the social and health care delivery system in the area.

Providers also noted that their young adult clients are more likely than other clients to reside outside the city of Seattle. Young adult survey respondents were almost twice as likely to report non-Seattle zip codes as older consumers, with 16% residing in East King County (versus 6% of older consumers) and 21% in South King County (versus 14%).

The population of youth/young adult PLWH is more racially diverse than the population of older PLWH. Although their caseloads are primarily white, providers noted growing numbers of African-Americans (and immigrant Africans), and increasing numbers of Latino clients. On the 2001 consumer survey, only 32% of PLWH between the ages of 13-24 identified as white, with 37% identifying as Latino and 21% as African-American. In contrast, 73% of older survey respondents identified as white, with 27% identifying as persons of color.

Due to the low numbers of HIV-infected adolescents in the EMA, the small number of responses from 13-24 year olds on the 2001 consumer survey (n=19) was not surprising. As a result, it is difficult to effectively quantify specific service needs of this population. However, of this sample population, 94% stated that they are currently receiving primary care for their HIV. A significantly higher percentage of 14-24 year old respondents noted that they were HIV+ and asymptomatic than did older PLWH (68% versus 29%). It is therefore not surprising that the percent of young PLWH taking prescription medication was much lower than for older PLWH

(47% of young adults taking antivirals and 21% taking protease inhibitors, versus 80% and 54% respectively for older PLWH). Providers reported that less than half of their young adult clients are on HAART therapy, and that adherence rates are relatively low even among those clients who have decided to begin combination therapy.

According to focus group participants and provider reports, access to the spectrum of medical, pharmaceutical and ancillary services is not a significant problem for their young adult clients. A large majority of HIV-infected youth/young adults who know their serostatus are connected with and are receiving medical care. Most of these clients are experiencing few, if any, health problems related to their HIV status. Providers reported that there is very little HIV-related morbidity in this population.

Utilization of case management services is very high among young adults with HIV, particularly for young women. Seventy-four percent of 14-24 year old PLWH reported using case management services on the 2001 survey. Case managers for young PLWH report that their clients are extremely dependent on them for service access and require that the case manager initiate contact with almost all other services.

Although providers report that mental health issues and multi-drug substance use are high in this population, low percentages of youth/young adult survey respondents report utilization of mental health or substance use services. Only 16% of young adult survey respondents stated that they are using substance use treatment services, and 37% reported using mental health counseling. Clients tell their case managers that they are willing to accept referrals to these services, but rarely follow through after the initial visit. Despite the low rate of follow-through, providers stated that they are seeing incremental change in the percent of young clients who are willing to accept mental health services. They also noted that providers of mental health care have become more accessible and willing to work with young adult PLWH in recent years.

Drug and alcohol use continues to be widespread in the population. Providers reported that almost all of their young adult clients have some history of substance use, ranging from recreational drug use to heroin addiction. Pregnancy has been the key factor in encouraging young female PLWH to enter substance use treatment; results for young males entering treatment have been mixed.

3. Service Priorities

Unlike prior years, young adult consumers identified service priorities that were relatively similar to those identified by older PLWH. Dental care emerged as the top service priority for this population, followed by case management, primary medical care, insurance programs and housing assistance (Table 49). Providers of services to young adult PLWH were in agreement about these priorities. In particular, they stressed the importance of providing targeted case management services to this population. Without ongoing, highly involved case managers, most of the young adult PLWH would fail to connect with the HIV service system.

“I know I wouldn’t have the knowledge and skills to get by on my own if my case manager was no longer available. It’s so helpful to have your case manager do the

looking and searching for you. Once I found out I was positive, I just didn't feel like doing anything but now I have my case manager there to do it.” (Young adult male PLWH)

Focus group participants echoed the importance of case management. The participants noted that their case manager not only assisted them in finding out about services, but also frequently accompanied them to appointments, was available for emotional support, and acted as both a friend and mentor.

**Table 49. Service Priorities: Youth and Young Adults (Age 14-24)
(n=19; 0 missing cases)**

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Dental care	13	68%
2	Case management	12	63%
3 (tie)	Ambulatory/outpatient medical care	11	58%
3 (tie)	Insurance programs	11	58%
3 (tie)	Housing assistance/related services	11	58%
6	Client advocacy	9	47%
7	Drug prescription program (ADAP)	7	37%
8	Mental health therapy/counseling	6	32%
9 (tie)	Direct emergency financial assistance	4	21%
9 (tie)	Food/meals	4	21%
9 (tie)	Counseling (emotional support)	4	21%

4. Service Gaps

Young adult respondents to the consumer survey identified gaps in a wide range of services. The most frequently cited gaps were alternative therapies, client advocacy, housing assistance, and food and meal programs (Table 50).

Young adult focus group participants noted difficulty in obtaining access to non-Western medical care. Several of the youths expressed distrust of the traditional medical care system, and favor alternative care over Western medical care. They noted that it is difficult for them to afford this type of care, and were upset by what they perceived as an anti-naturopathic bias on the part of their primary care providers.

“I feel overwhelmed by my condition, but I have hope about the medications. I am worried about being discriminated against or abused.”” (Young adult homeless female PLWH)

Lack of housing has been and remains a major problem for youth and young adult PLWH. Due to their age, lack of rental history and reliable incomes, most youth cannot qualify for housing

programs. Additionally, because most young adult PLWH are not yet AIDS-disabled, they do not meet eligibility requirements for placement in most AIDS housing facilities. As a result, many of the youth continue to live in unstable family situations, on the street, in shelters, or “couch surfing” with friends. Providers noted that, for this population, housing stability is directly tied to medical access. Getting their young adult clients to maintain access to health care was described as “almost impossible” in the absence of stable living situations.

**Table 50. Service Gaps: Youth and Young Adults (Age 14-24)
(n=19)**

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Alternative, non-Western therapies	7	37%
2 (tie)	Client advocacy	6	32%
2 (tie)	Housing assistance/related services	6	32%
2 (tie)	Food/meals	6	32%
5 (tie)	Referral	5	26%
5 (tie)	Treatment adherence support	5	26%
5 (tie)	Mental health therapy/counseling	5	26%
8 (tie)	Dental care	4	21%
8 (tie)	Insurance programs	4	21%
10	Direct emergency financial assistance	3	16%

Lack of access to food and meal programs emerged as a major service gap, identified by both consumers and providers. Young adult survey respondents were over three times more likely than older adults to identify gaps in this service (32% versus 9%). This is particularly true for young PLWH who lack permanent housing and cannot get home-delivered meals, or those who live outside central Seattle and do not have easy access to grocery pick-up programs.

Two services that were significantly more likely to be identified as gaps by young adult PLWH than older consumers were referral resources (26% versus 9%) and treatment adherence support (26% versus 4%). In general, young focus group participants were unaware that referrals to medical and dental care providers were available from the AIDS Care Access Project. As noted by providers, medication adherence is a major issue among this population, most of whom do not have the same kind peer support available to sustain their medication compliance as older consumers do.

Although access to primary medical care per se was not identified as a service gap, providers and focus group participants noted that discomfort in standard medical care settings was fairly common among young adult PLWH. Hospital clinic settings were described as “unfriendly” and “scary” for adolescent PLWH, most of whom are unfamiliar with the medical care system. Providers noted that teen and young adult clinics are needed to provide a welcoming, non-threatening environment for their young adult clients.

5. Access Barriers

Age was identified as the main access barrier for youth and young adult PLWH by providers and focus group participants. Although focus group participants stated that could access almost all services when needed, they expressed discomfort in accessing services which they feel are targeted to adults in their 30's-40's. They did note that the situation has improved for young adult PLWH in the past few years, but that communication between providers and young adult PLWH still needs to be improved.

“The perfect thing would be to have someone there a lot who knows everything that will happen. I’d love for someone to be able to come to my house for any question that would come up. A person to call on at all times.” (Young adult male PLWH)

As with other populations, lack of information emerged as the main access barrier identified by young adult survey respondents (Table 51). As noted previously, young adult focus group participants were often unaware of the services available in the Continuum of Care, and were highly dependent on their case managers to help them access services.

**Table 51. Access Barriers: Youth and Young Adults (ages 14-24)
(n=19)**

BARRIER	# OF VOTES	% OF RESP.
Lack of information	6	32%
Financial (can't afford it)	4	21%
Waiting list; not enough services	2	11%
Conflicts with schedule	2	11%
Haven't asked	2	11%
Eligibility (based on disability status)	2	11%

Providers noted that general life chaos served as a barrier to accessing services for the majority of their young adult clients. Most of the young adult consumers have unstable home environments, with few caring adults available to help them navigate the medical and social services systems. As noted by one provider, “Remembering [appointments] is tough, due to homelessness and chaotic lives. Medical care is just not a priority for youth.”

Financial constraints can also serve as a barrier. As noted previously, the large majority of young PLWH have little or no personal income. Money management skills in this population are virtually non-existent, according to providers. As a result, what little money these clients do have is spent either on necessities (such as food, rent, and clothing), recreational activities, or drugs. There is rarely money left over for co-pays for medical or other clinical care.

Providers and consumers offered several suggestions about how to improve service delivery and access for youth and young adult PLWH:

- Increase and maintain access to youth-focused case management. Acknowledge that effective case management for this population is labor- and time-intensive, and requires extensive outreach.
- Youth service providers must be prepared to focus on support and advocacy for their clients within the broader service system. This involves creating ongoing, intensive linkages with other service providers to ensure that client needs are expressed and understood.
- Develop a comprehensive system of care for youth and young adults. The more different agencies a young person has to deal with, the greater the likelihood that s/he will fall through the cracks. Providers of individual services, particularly medical care, need to realize that compartmentalizing service delivery will not work for this population.
- Demonstrate flexibility in working with young adult PLWH. The client might be difficult to locate, appointments might be missed and communication might be inconsistent and frustrating. Trust takes time to build, and only through building trust will young clients maintain access to the system.

GLOSSARY OF HIV-RELATED SERVICE CATEGORIES

Approved March 1, 2001

Adult Day Health: Home- or facility-based therapeutic, nursing, supportive and/or compensatory health services provided in accordance with a written, individualized plan of care. Adult day health/day care services are those services or activities provided to adults who require care and supervision in a protective setting for a portion of a 24-hour day. Component services or activities include opportunity for social interaction, companionship and self-education, health support or assistance in obtaining health services, counseling (including mental health and substance use counseling), medication management, recreation and general leisure time activities, meals, personal care services, plan development and transportation.

Alternative/Non-Western Therapies: The provision of primary or complimentary non-allopathic medical care and medicinal treatments designed to enhance the immune system, reduce the incidence of opportunistic infections, relieve debilitating symptoms of HIV/AIDS (such as pain, fatigue, neuropathy and diarrhea), ameliorate medication side effects and provide mental/emotional care to reduce depression, anxiety and despair, including naturopathy, acupuncture, Traditional Chinese Medicine (TCM).

Ambulatory/Outpatient Medical Care: The provision of professional diagnostic and therapeutic services rendered by a physician, physician's assistant, clinical nurse specialist or nurse practitioner in an outpatient, community-based and/or office-based setting. This includes diagnostic testing, early intervention and risk assessment, preventative care and screening, practitioner examination, medical history taking, diagnosis and treatment of common physical and mental conditions, prescribing and managing medication therapy, care of minor injuries, education and counseling on health and nutritional issues, minor surgery and assisting at surgery, well-baby care, continuing care and management of chronic conditions, and referral to and provision of specialty care. The provision of primary medical care must be consistent with Public Health Service guidelines.

Case Management: A range of client-centered services that links clients with health care, psychosocial and other services to ensure timely, coordinated access to medically appropriate levels of health and support services, continuity of care, and ongoing assessment of the client's and other family members' needs and personal support systems, and in-patient case management services that prevent unnecessary hospitalization or that expedite discharge, as medically appropriate, from in-patient facilities. Key activities include: initial comprehensive assessment of the client's needs and personal support systems; development of a comprehensive, individualized service plan; coordination of the services required to implement the plan; client monitoring to assess the efficacy of the plan; and periodic reevaluation and revision of the plan as necessary over the life of the client. May include client-specific advocacy and/or review of utilization of services.

The information and assistance component of the program is the entry point to other case management services and is also responsible for promoting community awareness of program services. Information and assistance is provided to individuals with HIV infection who (a) are able to locate and access needed services with sufficient information, or (b) do not require ongoing case management but need someone to assist them or act on their behalf in order to obtain needed services or benefits or (c) need to be screened to determine if they should be referred for a comprehensive assessment. Key activities include: information giving, screening, service referral and assistance (when client will not receive other case management services), client advocacy and community resource information systems.

Child Care: Home- or community-based non-medical assistance designed to relieve or replace the primary care giver responsible for providing day-to-day care of the client or client's children.

Client Advocacy: A client-centered, single-issue service provided on an intermittent basis. Service provided might include assistance in obtaining: financial/benefits counseling, interpreter services, peer or client advocacy, and medical and/or treatment information. To prevent duplication of case management services, client advocacy does not involve coordination and follow-up on medical treatments or other ongoing psychosocial needs.

Counseling/Emotional Support: Individual and/or group counseling services other than professional mental health counseling, which is provided to clients, family and/or friends by non-licensed counselors. May include psychosocial providers, peer counseling/support group services, caregiver support/bereavement counseling, and/or drop-in counseling.

Dental Care: Diagnostic, prophylactic and therapeutic services rendered by dentists, dental hygienists and similar professional practitioners.

Direct Emergency Financial Assistance: Provision of short-term payments to agencies, or establishment of voucher programs to assist with emergency expenses related to food or utilities. These allocations must be monitored to assure emergency needs, limited amounts, limited use, and for limited periods of time.

Drug Reimbursement Program: On-going service/program to pay for approved pharmaceuticals/medications for persons who are un- or under-insured.

Food/Meals: Provision of food, meals, or nutritional supplements (not finances to purchase food or meals, nor nutritional services).

Health Education/Risk Reduction: Education and other risk reduction interventions targeted to individuals living with HIV to reduce the spread of HIV or the acquisition of STDs or new strains of HIV. Services must be provided to HIV+ persons in the context of one of the following HIV care service programs: HIV ambulatory/outpatient medical or alternative care, case management, mental health therapy/counseling, or substance use treatment/counseling. Services must be acceptable and appropriate to the individual client. Strategies used should be considered effective for the target population according to scientific literature on HIV prevention.

Home Health Care: Therapeutic, nursing, supportive and/or compensatory health services provided by a licensed/certified home health agency in a home/residential setting in accordance with a written, individualized plan of care established by a case management team that includes appropriate health care professionals. Component services can include homemaker, home health aide and personal/attendant care.

Housing Assistance/Housing-Related Services: Assistance in locating, obtaining and/or maintaining suitable emergency, transitional or on-going shelter (such as assisted and/or group living situations, Section 8 programs). Includes costs associated with finding a residence and/or subsidized rent in the form of short term or emergency financial assistance to support temporary housing to enable the individual or family to gain and/or maintain medical care.

Insurance Programs: Financial assistance program to assist eligible low income individuals with HIV disease in maintaining a continuity of health insurance or receiving medical benefits under a health insurance program including risk pools. Assistance shall not be utilized to pay any costs associated with the creation, capitalization, or administration of a liability risk pool and to pay any amount expended by a State under Title XIX of the Social Security Act.

Legal Services: Legal services directly necessitated by a person's HIV status including: preparation of Powers of Attorney, Do Not Resuscitate Orders, wills, trusts, bankruptcy proceedings, and interventions necessary to ensure access to eligible benefits, including discrimination or breach of confidentiality litigation.

Mental Health Therapy/Counseling: Psychological and psychiatric treatment and counseling services, including individual and group counseling, offered by a licensed, professional mental health provider licensed or authorized within the State, including psychiatrists, psychologists, clinical nurse specialists, social workers and counselors.

Outreach: Outreach programs that have as their principal purpose identification, education and referral of persons with HIV disease so that they may be enrolled and retained in care and treatment services. Outreach programs must: be planned and delivered in coordination with local HIV prevention outreach programs to avoid duplication of effort, be targeted to populations known through epidemiological data to be at significant risk for HIV infection, and be conducted at times and in places where there is a high probability that HIV-infected individuals will be reached.

Referral: The act of directing a person to a medical, dental, or other provider, in person or through the phone, written or by other types of communication.

Substance Use Treatment/Counseling: Provision of treatment and/or counseling to address substance abuse (including alcohol) problems, provided in an outpatient or residential health service setting.

Transportation: Conveyance services provided to a client in order to access health care or psychosocial support services. May be provided routinely or on an emergency basis.

Treatment Adherence Support: Provision of counseling or special programs to ensure readiness for and adherence to complex HIV/AIDS treatments.

Volunteer Home Chore: Activities provided by volunteers/peers to assist the client in performing household tasks.

“NOT IN CARE” PROJECT

Background

- Goal: To determine why some PLWH don't get medical care for their HIV
- Impetus for project based on anecdotal reports from service providers that some of the clients they work with are not receiving medical care
- Project sponsored by Seattle EMA HIV/AIDS Planning Council; joint project of the Council's Care and Prevention Planning Committees and the Collaboration Committee
- Planned as adjunct project to the Y2K Care/Prevention Collaboration Needs Assessment

Methods

- Administered interview; each approximately 5 minutes
- Instrument created by work group of Collaboration Committee, with input from members of the Evaluation Committee
- Questions focused on:
 - Main and secondary reasons why participants were not in care
 - What would have to change in order for them to access care
 - Client demographics
- Clients identified and interviews conducted by staff/volunteers at participating agencies (particularly outreach workers)
- 30 agencies enlisted to participate:
 - 11 HIV prevention agencies
 - 9 HIV care service agencies
 - 10 agencies external to the HIV/AIDS Continuum
- Interviews conducted from mid-April through end of June 2000

Demographics

27 total interviews conducted

SEX:

- 23 male
- 3 female
- 1 transgendered (Male-to-female)

RACE/ETHNICITY:

- 17 Caucasian/White
- 6 African-American/Black
- 3 Asian/Pacific Islander
- 2 Latino/Latina

AGE RANGE:

- 9 20-29 years old
- 9 30-39
- 7 40-49
- 2 Unknown

MODE OF TRANSMISSION:

- 12 MSM
- 6 IDU
- 6 MSM/IDU
- 2 Heterosexual (male-to-female)
- 1 Unknown

LENGTH OF TIME KNOWN HIV+:

- 2 Under one year
- 5 1-2 years
- 7 Between 2-5 years
- 9 Over 5 years
- 4 Unknown

Main Reasons for Not Getting Medical Care HIV

- 7 Don't need it
- 4 Lack of trust in doctors
- 3 Have more important things to deal with
- 2 Don't trust HIV medications
- 2 Can't afford it

No respondents stated that they did not know where to access care

Overall Reasons for Not Getting Care

- 15 Lack of trust in doctors
- 13 Don't trust HIV drugs
- 12 Don't want to be judged about drug use
- 11 Don't need it
- 9 Can't afford it
- 9 Worried someone I know will find out
- 8 Have more important things to deal with
- 8 Embarrassed about having HIV
- 5 Nothing they can do to help me
- 5 Dissatisfied with previous care

Several other reasons were mentioned by 3 or fewer respondents

What would have to change for you to get medical care

- 8 I'd have to get sicker
- 6 Change in provider attitudes
- 6 Different drugs or treatment regimens available
- 3 I'd have to get stable housing

Reasons for Not Getting Care by Sub-Population

MSM (n=12)

- 7 Don't need it
- 5 Can't afford it

IDU (n=6)

- 4 Lack of trust in doctors
- 3 Don't want to be judged about drug use
- 3 Don't trust HIV drugs
- 3 Nothing they can do to help me

MSM/IDU (n=6)

- 6 Don't want to be judged about drug use
- 5 Don't trust HIV drugs
- 5 Lack of trust in doctors
- 4 Worried someone I know will find out
- 3 Worried government will know

Reasons for Not Getting Care by Race/Ethnicity

Caucasian/White (n=17)

- 8 Don't want to be judged about drug use
- 8 Don't trust HIV drugs
- 7 Lack of trust in doctors
- 6 Can't afford it
- 5 Have more important things to deal with

People of Color (n=11)

- 8 Lack of trust in doctors
- 7 Don't need it
- 6 Worried someone I know will find out
- 5 Don't trust HIV drugs

WHAT WE LEARNED

- Many agencies told us they could not identify any clients who were not accessing medical care
- Very few participants are not using medical care because they could not access it
- The main reasons people are not using care are because they feel they do not need it, or they do not trust the medical system and/or the treatments available
- Efforts to move PLWH into the care system and maintain participation need to address these issues

WHAT WE DID RIGHT

- Involving both HIV care and prevention agencies
- Reaching out beyond the traditional HIV prevention and care continuum
- Using outreach workers to identify potential participants and conduct interviews
- Developing the instrument as an administered interview instead of self-completed survey
- Keeping the instrument short and straightforward

WHAT WE COULD HAVE DONE DIFFERENTLY

- Involving more people as core oversight group (including Planning Council members)
- Framing the project more fully on its own, rather than as an adjunct to the Care/Prevention Collaboration Project
- Having more lead time
- Spending more time laying the groundwork with individual agencies
- Establishing broader eligibility requirements for potential interviewees at beginning of project, instead of in process

WHAT WE DON'T KNOW WHAT TO DO ABOUT

- Focused efforts were made to solicit input and recruit participants from a wide range of agencies and populations, particularly from agencies whose staff has reported working with clients who are having trouble accessing care
- Responses from many of these agencies was minimal

THE 2000 HIV/AIDS CARE AND PREVENTION COLLABORATION PROJECT

Background:

King County has a national reputation for its successful HIV/AIDS care and prevention system. As the demographics of the HIV epidemic continue to change and local data show increasing STD and HIV co-infection rates among men who have sex with men (MSM), local providers and planners sensed a need to increase collaboration between HIV/AIDS prevention and care systems. Thus, the Ryan White Title I HIV/AIDS Planning Council (“the Council”) in Seattle undertook a care and prevention collaboration needs assessment in the first quarter of 2000. The assessment, called the “Collaboration Project,” was jointly conducted by the Council and Public Health – Seattle & King County, the Ryan White Title I grantee.

The project aimed to see if care service providers discuss sex and drug use risk reduction with their HIV+ clients, and make appropriate referrals for clients whom they determine have ongoing risk reduction needs. The project also examined whether prevention workers who encounter HIV+ individuals in their work appropriately refer these clients into the care service delivery system. The project explored whether referrals were happening across systems, whether those referrals were effective, and what barriers stood in the way of effective referrals. Once barriers to cross-system referrals were identified, the final project goal was to determine what changes can be made, to improve the resource linkage and referral capacity for each of these HIV/AIDS systems.

Methods:

The Council convened a Collaboration Work Group including members of both the care and prevention sides of the Council, including persons living with HIV/AIDS, to develop and oversee the project. The assessment consisted of a series of one-on-one phone or in-person interviews with providers from the prevention and care systems, and follow-up focus groups with care and prevention interview subjects and HIV+ consumers to construct solutions to barriers and problems identified in the interview process.

Two staff members of the PHSKC HIV/AIDS Program conducted the interviews, along with two contract interviewers, one familiar with HIV care programs, and one familiar with the prevention field. The Council sought to interview 102 providers, from the spectrum of care services; 74 interviews were actually conducted (72.5% of target), and also sought to interview 46 prevention providers; 31 prevention provider interviews were completed (67.3%). Interviews conducted during January and February 2000 took about 20-25 minutes each.

Results of Provider Interviews:

Demographic data revealed notable differences in the populations of care and prevention providers, and the ways in which services are delivered: Provider Gender: Care service providers were twice as likely to be female than prevention providers (53% versus 26%). Provider Race/ethnicity: Prevention providers are much more racially diverse than those in the care system. Over half of the prevention providers interviewed identified as non-white (48% Caucasian, 26% Latino/a, 13% American Indian or Alaska Native, 10%

Asian/Pacific Islander and 10% African American). In contrast, 82% percent of the care providers interviewed were Caucasian, with far smaller numbers of persons of color (4% Asian/Pacific Islander, 3% Latino/a, 1% African-American and 1% American Indian/Alaska Native). Thus, the care provider population is fairly similar to the demographics of King County as a whole, while the demographics of the prevention system are more representative of the epidemic trends in populations at risk for HIV. This suggests that clients being referred into the care system by prevention workers are less likely to encounter providers from their ethnic and cultural backgrounds.

Populations served: Unlike care service providers, all prevention providers focus activities on specific target populations. The most frequently targeted populations were MSM (61%), communities of color (35%), and injection drug users (IDU, 19%), with smaller numbers of providers targeting women, youth and adolescents, and HIV+ individuals. In contrast, 68% of care providers stated that they do not work with a specific target population, instead offering services to all eligible clients.

Job focus: Prevention providers are much more likely than care service providers to engage in more than one form of service provision. Half (48%) of the prevention providers interviewed engaged in multiple activities (e.g., doing outreach and giving presentations or performing both individual and group level counseling.) Only 8% of care service providers reported performing multiple activities, instead focusing on specific job functions (e.g., case management, primary medical care, mental health therapy, peer counseling, substance use treatment and counseling, etc.).

Previous history of service delivery: Forty-two percent of prevention providers interviewed had previously worked in the care service arena, while only 11% of care providers had previously performed prevention activities. This suggests that prevention workers may be more likely to know about care services (e.g., types of programs, methods, expected outcomes) than care workers are to know about prevention services.

Referral Capacity between Systems:

We asked prevention providers if they had offered any referrals to medical care or other services in the past year, defining a “referral” as giving a client the name and/or phone number of a *specific provider or provider agency*, rather than just suggesting that the individual needed care. Ninety percent of the prevention providers interviewed said that they had made a care referral in the past year. (The 10% who had not were providers who stated that none of their clients reveal their HIV status.)

The most common referral was for medical care; about 70% of providers made specific medical care referrals. Sixty-one percent of respondents made case management referrals, 50% made referrals for housing assistance, 46% referred clients for mental health therapy, and 46% made referrals for substance use treatment. Smaller numbers made referrals to emotional support programs (21%), insurance programs (21%), complementary therapies (14%), food and meal programs (11%), and various other services. Eleven other services were mentioned once or twice.

To find out if prevention providers who make referrals are referring their clients to the appropriate programs, the interview asked “Where would you refer clients for each of the following services?” Providers were instructed to name as many service providers within each category as they knew. In general, referral sources were most appropriate in the areas of HIV counseling and testing, medical care, and case management. Prevention workers were less likely to identify available mental health and substance use resources. Of particular concern was the limited awareness prevention workers had about referrals to medical insurance programs (such as the Early Intervention Insurance Program and the Evergreen Insurance Program) and Washington State’s AIDS Prescription Drug Program.

Care providers were less likely to have made referrals for clients into prevention/risk reduction programs than prevention providers were to have made referrals into care. While 90% of prevention providers had made referrals into the care system, only 43% of care providers referred clients into sexual risk reduction services. Many fewer volunteers (7%) than paid staff (51%) made risk reduction referrals.

Most of the sexual risk reduction referrals made by care providers seemed to be appropriate. The majority were to programs targeting gay/lesbian/bisexual/ transgender (GLBT) individuals. Providers who were asked follow-up questions about the specific programs or methods offered by these agencies were relatively unaware of the specific nature of the programs to which they were referring. Care providers seemed to need as much information about prevention programs as prevention providers needed about care service referrals.

Two-thirds (66%) of care providers referred a client during the past year to a program that addressed drug use risk reduction. Seventy-eight percent of paid staff had made such a referral, versus 14% of the volunteers. Similar to referrals for sexual risk reduction, the largest number of referrals for substance use treatment and counseling were made to agencies targeting the GLBT population.

Barriers to Inter-System Collaboration:

We asked prevention workers about the barriers they encountered in making referrals to care services. Cultural and language barriers were a main concern, particularly for providers targeting clients of color (23%). When prevention workers refer clients into the care system, these clients may encounter providers who neither speak their language nor understand their cultural backgrounds. Nineteen percent of the interview subjects said that needed services were not available. This may represent a lack of information, since the King County care continuum is fairly comprehensive and prevention providers might be unaware that services are actually available. Nineteen percent stated that they did not know where to make appropriate referrals, and 16% expressed concerns about client confidentiality.

Focus group participants offered several suggestions about improving the relationship between prevention and care providers. They urged care and prevention providers to conduct presentations at each other’s agencies to establish resource linkages. Prevention

providers also wanted to see care service agencies make a commitment to changing their staffing patterns to increase diversity, which means paying increased attention to recruitment, hiring and training.

Some prevention providers were very concerned about “handing off” clients to the care service continuum. Despite lengthy up-front work to actually get a client into the care system, once that client enters the care system the prevention worker may no longer be seen as a valuable resource. When the prevention provider has established a relationship with the client, these prevention providers suggested that the care provider (including the client’s case manager) consider the prevention provider as part of the client’s immediate support system and involve the prevention provider in client consults.

When care service providers were asked about barriers they faced in making referrals to HIV risk reduction programs, over a third (38%) lacked information about available programs. They lacked knowledge about specific agencies to which referrals could be made, as well as lack of familiarity with the kinds of programs offered by these agencies. Nineteen percent of care providers said their clients were resistant to or not interested in risk reduction programs. Care providers interviewed and in focus groups expressed desire for in-service training offered by prevention agencies, particularly inter-agency presentations between care and prevention providers. This kind of approach would allow them to become familiar with other agencies’ staffs, identify key resource persons to whom they could make referrals, and learn about the range of prevention programs.

Care Providers’ Discussion of Sexual and Drug Use Issues with Clients: Asked about discussing sexual risk reduction, a quarter (26%) said they discuss sexual risk reduction with all their clients. Eight percent said they never discuss risk reduction with any clients, while 23% said they discuss it with less than one-quarter of their clients. An important distinction was that 66% of paid staff discussed sexual risk reduction with at least half of their clients, versus only 36% of volunteers.

Smaller numbers of care providers reported inquiring about STD risks from their clients. Only 18% ask all clients about risk behaviors related to STD transmission, and 11% discuss STD risk reduction with clients. Some providers stated that since they already have this information in the client’s chart, they did not re-initiate a discussion. However, it is unclear if these providers continued to discuss ongoing risk potential with their clients. Again, most (59%) paid staff discussed STD risk reduction with clients, versus only 14% of volunteers.

Barriers to offering clients sexual risk reduction messages that providers mentioned most were client-, rather than provider-related. The largest barrier identified was perceived client discomfort in talking about sex, mentioned by 35% of providers. Sixteen percent mentioned that clients’ might perceive personal guilt or shame discussing sexual behaviors. Fifteen percent believed that male clients might feel uncomfortable talking to female providers about sexual issues. An additional 15% of providers, mostly volunteers, said that discussing sexual behaviors and risk reduction with clients was not part of their job.

A much higher percentage of care providers discuss drug using behaviors and risk reduction with their clients. Nearly half (47%) initiated discussion about drug related behaviors with all clients. Only 15% never initiated discussion about drug use behaviors. Again, 56% of paid staff inquired about drug use from all of their clients versus only 7% of volunteers.

To questions about barriers to discussing drug use related risks and what might help overcome these barriers, most barriers mentioned were client-related, including clients' denial of drug use (identified by 23% of providers), clients' fear of being judged or of reprisals being levied against them (23%), general resistance to talking about this topic (22%), and shame about using drugs (19%). Only 8% of providers identified personal barriers, in this case their own negative attitudes towards drug use and IDU.

Two follow-up focus groups interviewed twenty-three care providers, including 13 females and ten males, all of whom were white. Participants wanted sexual and drug use behavior and risk reduction discussions formalized into their jobs, with questions on these topics included in all initial client assessments and periodic re-assessments. They also wanted to see provider trainings around various sexual counseling issues. Care providers also wanted more training on substance use issues and increased linkages between the HIV and substance use systems.

Consumer focus groups:

Project staff followed up the prevention and care provider focus groups with two focus groups of HIV+ consumers to expand on issues brought up by providers, and to see if consumers could offer additional solutions to the problems identified in provider interviews. A total of 22 consumers attended the groups, including 17 males and five females. At least ten of the participants were persons of color.

To feel comfortable discussing sexual risk behaviors, focus group participants reiterated the need for trust to be developed between providers and clients. There was unanimous agreement among focus group participants that it was always appropriate for medical care providers to bring up these issues, since they felt that confidentiality was guaranteed in the medical setting. If consumers understood that medical providers routinely inquired about these issues with patients, no one would feel singled out.

Consumers felt it was only acceptable for case managers to discuss sexual and drug use risk reduction issues with clients if trust had been established. They felt it was very important for case managers to explain how and where this information would be used. Some clients expressed concerns that revealing unsafe sexual behaviors to non-medical providers, such as case managers and mental health therapists, would lead to providers "policing" their clients. This discussion evoked confidentiality and privacy concerns brought up in Washington State around the recent implementation of named reporting of HIV positive persons.

Consumers expressed mixed sentiments regarding the appropriateness of discussing sexual and drug use risk reduction with other types of providers. Most felt it was suitable for mental health providers to discuss sexual and drug use issues if the client brings it up, but were concerned that mental health professionals might be judgmental about client behaviors. Clients felt it was important for substance use counselors to address all types of drug use risk reduction, but felt it was only appropriate for substance use counselors to ask about sexual risk behaviors as they related to the client's alcohol and drug use. Participants felt it was important for peer counselors to be knowledgeable about these issues, particularly when the client brings them up.

Summary:

This needs assessment taught the Planning Council and PHSKC much about the current nature of the care and prevention systems, and their overlap. The study identified successes in the current inter-system resource and referral processes, and highlighted collaboration and communication gaps between the two systems. The project also identified concrete suggestions about how the entire continuum of HIV prevention and care services might work collaboratively to make improvements.

Given increasing national evidence of complacency about sexual risks and local data that many MSM with STD also carry HIV, the fact that so few care providers discuss these risk issues is a great concern. With evidence on the relationship between STD prevention and HIV prevention, as well as the possibility of re-infection and illness progression, it is increasingly important for providers to discuss sexual risks with their clients in an ongoing fashion – an area to address in care provider training.

Based on the findings of the Collaboration Project, the Council has implemented several changes in the King County prevention and care continuum of service delivery in the upcoming year. These include:

- Reserving \$65,000 in Ryan White Title I funding to train care providers on how to more effectively address sexual and drug use risk reduction with clients;
- Attaching caveats to FY2001 funding in the Ryan White service categories of ambulatory care and substance use, to ensure that favorable consideration will be given to proposals which demonstrate strategies to train staff to assess risk reduction issues and successfully incorporate counseling and/or referral and follow-up for prevention services;
- Using CDC funds to develop and implement prevention case management programs at the Harborview Madison Clinic and Northwest AIDS Foundation, to help HIV+ clients who need and want further risk-reduction counseling and assistance, and
- Assigning ongoing committee status to the Collaboration Work Group (now called the Collaboration Committee), to ensure that care/prevention collaboration and coordination issues are a continuing topic of discussion for the entire Council.

We recommend that other municipalities and care and prevention planning groups consider undertaking a similar process in their community.

For more information about the Collaboration Project, please contact Jeff Natter at (206) 205-5506.

Submitted by Jeff Natter, MPH, Theresa Fiano, Barb Gamble, MPA and Bob Wood, MD.

2001 HIV/AIDS Consumer Survey

Make your voice heard!



***Influence funding
decisions that affect you!***

Are you living with HIV or AIDS?

If so, the Planning Council wants to know what services you use or need to help you get or keep health care. The Planning Council is a community group made up of people with HIV/AIDS and service providers. They decide how money from the Ryan White CARE Act gets spent in King County.

You can reach us at (206) 206-4527 or TTY (206) 205-5552

Please return this survey by January 31, 2001

**ALL RESPONSES ARE STRICTLY ANONYMOUS.
PLEASE DO NOT SIGN YOUR NAME ANYWHERE
ON THE SURVEY FORM.**

PART 1: WHAT SERVICES ARE YOU USING? WHAT CAN'T YOU GET?

STEP 1:

On the following pages, you'll find a list of services for people living with HIV/AIDS. For **each** of the services listed, put an "X" in **one** of the three boxes to tell us:

- if you currently need the service and are using it OR
- if it's a service you currently don't need OR
- if it's a service that you need, but can't get.

STEP 2:

For each service that you checked "Need, can't get," tell us the reason you feel you can't get this service. ***If you don't tell us what's wrong, we can't fix it!***

Some of the reasons people have mentioned include:

- Can't afford it
- Live too far away
- Don't feel welcome at the agency
- Don't know where to get it
- Not sick enough
- The service doesn't meet my needs

You can also mention other reasons.

EXAMPLE:

Service	Need and use	Don't need	Need, can't get	Why I can't get it... (It's IMPORTANT that you tell us!)
Dental care				
Support groups				

MEDICAL AND RELATED SERVICES

Service	Need and use	Don't need	Need, can't get	Why I can't get it... (It's IMPORTANT that you tell us!)
Medical care (doctor, nurse, etc.)				
Naturopathy, herbal medicine, etc.				
Acupuncture or Chinese medicine				
If you are currently using naturopathy, herbal medicine, acupuncture or other non-Western therapies, do you consider this to be your <u>primary</u> form of medical care?				
				Yes <input type="checkbox"/> No <input type="checkbox"/>
Dental care				
Treatment adherence support (help taking your HIV meds correctly)				
WA State prescription drug program ("APDP")				
Help paying for medical insurance				
Home nursing or infusion care				
Skilled nursing facility				
Hospice care				
Massage therapy				
Nutritional counseling				

IN-HOME SERVICES

Service	Need and use	Don't need	Need, can't get	Why I can't get it... (It's IMPORTANT that you tell us!)
Home chore <u>volunteer</u> (help with shopping, cooking, cleaning, etc.)				
Home care worker (<u>paid</u> attendant)				
Home delivered meals				

INFORMATION AND HELP GETTING SERVICES				
Service	Need and use	Don't need	Need, can't get	Why I can't get it... (It's IMPORTANT that you tell us!)
Medical information about HIV/AIDS, treatments, etc.				
Telephone referrals to medical or dental care				
Interpreter services				
Case management (having a professional help you get services and benefits)				
Peer or client advocacy (other than a case manager)				

COUNSELING, TREATMENT AND SUPPORT				
Service	Need and use	Don't need	Need, can't get	Why I can't get it... (It's IMPORTANT that you tell us!)
Professional mental health counseling or therapy				
Support groups				
One-to-one peer emotional support				
Spiritual or religious counseling				
Help <u>quitting</u> drug or alcohol use				
Help <u>managing</u> drug or alcohol use (harm reduction)				

HOUSING AND FINANCIAL HELP				
----------------------------	--	--	--	--

Service	Need and use	Don't need	Need, can't get	Why I can't get it... (It's IMPORTANT that you tell us!)
Help finding low income housing				
Help paying rent				
Help paying utility bills				
Help paying for groceries				
Benefits counselor – SSI, SSD, etc. (other than case manager)				

SUPPORT SERVICES				
------------------	--	--	--	--

Service	Need and use	Don't need	Need, can't get	Why I can't get it... (It's IMPORTANT that you tell us!)
Food bank/receiving free groceries				
Child care				
Transportation/rides				
Adult day health program				
Information/help with safer sex or safer drug use				
Legal assistance				

PART 2: WHAT SERVICES ARE MOST IMPORTANT TO YOU?

**Now we want to find out which services you consider to be MOST IMPORTANT for you.
You may check up to SEVEN (7) of the services listed below.
(Please don't check more than seven.)**

	Acupuncture or Chinese medicine		Information/help with safer sex or safer drug use
	Adult day health program		Interpreter services
	Benefits counselor (other than case manager)		Legal assistance
	Case management		Massage therapy
	Child care		Medical care (doctor, nurse, etc.)
	Dental care		Medical info about HIV, treatments, etc.
	Food bank/receiving free groceries		Mental health counseling or therapy
	Help finding low income housing		Naturopathy/herbal medicine/etc.
	Help managing drug or alcohol use (harm reduction)		Nutritional counseling
	Help quitting drug or alcohol use		One-to-one peer emotional support
	Help paying for groceries		Peer or client advocacy (other than case manager)
	Help paying for medical insurance		Prescription drug program of WA State ("APDP")
	Help paying rent		Skilled nursing facility
	Help paying utility bills		Spiritual or religious counseling
	Home care worker (paid attendant)		Support groups
	Home chore volunteer		Telephone referrals to medical/dental care
	Home delivered meals		Transportation/rides
	Home nursing or infusion care		Treatment adherence support (help taking HIV meds correctly)
	Hospice care		Other: _____

PART 3:
TELL US ABOUT YOURSELF
(Remember, your answers are strictly ANONYMOUS)

What is your sex? (Check one)

- | | |
|---------------------------------|---|
| <input type="checkbox"/> Male | <input type="checkbox"/> Transgendered (M-to-F) |
| <input type="checkbox"/> Female | <input type="checkbox"/> Transgendered (F-to-M) |

What is your race/ethnicity? (Check all that apply)

- | | |
|--|---|
| <input type="checkbox"/> African American/Black | <input type="checkbox"/> Asian/Pacific Islander |
| <input type="checkbox"/> Alaska Native | <input type="checkbox"/> Caucasian/White |
| <input type="checkbox"/> American Indian/Native American | <input type="checkbox"/> Latino/Latina |
| <input type="checkbox"/> Other: _____ | |

What is your home zip code? _____

What is your age? _____

What is your annual household income (before taxes)? (Check one)

- | | |
|--|--|
| <input type="checkbox"/> Under \$8,500 | <input type="checkbox"/> \$25,001 - \$30,000 |
| <input type="checkbox"/> \$8,501 - \$17,000 | <input type="checkbox"/> \$30,001 - \$40,000 |
| <input type="checkbox"/> \$17,001 - \$25,000 | <input type="checkbox"/> Over \$40,000 |

Do you have any dependent children living with you?

- ☐ No
- ☐ Yes If "yes," how many dependent children are living with you? _____
- What are their ages? _____

How do you believe you became infected with HIV? (Check all that apply)

- | | |
|--|---|
| <input type="checkbox"/> Sex with a man | <input type="checkbox"/> Blood transfusion |
| <input type="checkbox"/> Sex with a woman | <input type="checkbox"/> Blood products/clotting factor |
| <input type="checkbox"/> Sex with an injection drug user | <input type="checkbox"/> Don't know |
| <input type="checkbox"/> Sharing drug needles or works | <input type="checkbox"/> Other: _____ |

How do you identify yourself? (Check one)

- | | |
|--|---------------------------------------|
| <input type="checkbox"/> Straight/heterosexual | <input type="checkbox"/> Bisexual |
| <input type="checkbox"/> Gay/lesbian | <input type="checkbox"/> Other: _____ |

What is your HIV status? (Check one)

- ☐ HIV positive, without symptoms
- ☐ HIV positive, with symptoms
- ☐ AIDS diagnosed (based on low T-cell count)
- ☐ AIDS diagnosed (based on opportunistic infections)

What is your current T-cell count? (Check one)

- | | |
|-------------------------------------|--|
| <input type="checkbox"/> Don't know | <input type="checkbox"/> Between 200 - 500 |
| <input type="checkbox"/> Under 200 | <input type="checkbox"/> Over 500 |

What is your current viral load? (Check one)

- | | |
|--|---|
| <input type="checkbox"/> Don't know | <input type="checkbox"/> Between 1,001 - 10,000 |
| <input type="checkbox"/> Undetectable or below 200 | <input type="checkbox"/> Between 10,001 - 100,000 |
| <input type="checkbox"/> Between 200 - 1,000 | <input type="checkbox"/> Over 100,000 |

In the past twelve months, have you (Check all that apply):

- ☐ Been in jail or prison
- ☐ Been homeless (no permanent address)
- ☐ Used needles to inject street drugs
- ☐ Used other street drugs

Have you ever been diagnosed with a mental illness?

- ☐ Yes
- ☐ No

What kind of place do you currently live in? (Check one)

- | | |
|--|--|
| <input type="checkbox"/> Your own house or apartment | <input type="checkbox"/> Jail or prison |
| <input type="checkbox"/> In a friend or relative's house/apartment | <input type="checkbox"/> Drug/alcohol treatment center |
| <input type="checkbox"/> Hospice or nursing facility | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Live on the streets or in a shelter | |

Do you currently live in housing that you qualified for by having AIDS?

- ☐ Yes
- ☐ No

Are you currently taking any of the following medications for your HIV infection? (Check all that apply)

- ☐ Antiviral medications (AZT, ddI, d4T, nevirapirne, Combivir, Epivir, abacavir, Sustiva, etc.)
- ☐ Protease inhibitors (invidinavir (Crixivan), saquinavir, ritonavir, nelfinavir, Amprenavir, etc.)
- ☐ Drugs to treat or prevent opportunistic infections

Are you having problems taking your HIV meds as prescribed?

- ☐ No
- ☐ Yes

If "yes", what are the reasons? (Check all that apply)

- | | |
|---|---|
| <input type="checkbox"/> Too many pills | <input type="checkbox"/> Don't have stable housing |
| <input type="checkbox"/> I forget when to take them | <input type="checkbox"/> Don't like to be reminded I have HIV |
| <input type="checkbox"/> Bad side effects of the meds | <input type="checkbox"/> Too busy |
| <input type="checkbox"/> Afraid people will find out I have HIV | <input type="checkbox"/> Other: _____ |

What or who helps you to take your meds as prescribed? (Check all that apply)

- | | |
|--|---|
| <input type="checkbox"/> No one; I don't need any help | <input type="checkbox"/> Another HIV+ person |
| <input type="checkbox"/> Doctor/nurse | <input type="checkbox"/> Mediset (pill box) or timers |
| <input type="checkbox"/> Case manager | <input type="checkbox"/> Pharmacist |
| <input type="checkbox"/> Family/partner/roommate | <input type="checkbox"/> Other: _____ |

PART 4:

WHAT SERVICES HELP YOU GET OR KEEP MEDICAL CARE?

A lot more attention is being paid these days to helping people with HIV or AIDS get and keep the medical care they need.

Please tell us which services you think are the most important in helping YOU get medical care or keep the medical care you're using.

**You may check up to SEVEN (7) of the services listed below.
(Please don't check more than seven.)**

<input type="checkbox"/>	Acupuncture or Chinese medicine	<input type="checkbox"/>	Hospice care
<input type="checkbox"/>	Adult day health program	<input type="checkbox"/>	Information/help with safer sex or safer drug use
<input type="checkbox"/>	Benefits counselor (other than case manager)	<input type="checkbox"/>	Interpreter services
<input type="checkbox"/>	Case management	<input type="checkbox"/>	Legal assistance
<input type="checkbox"/>	Child care	<input type="checkbox"/>	Massage therapy
<input type="checkbox"/>	Dental care	<input type="checkbox"/>	Medical info about HIV, treatments, etc.
<input type="checkbox"/>	Food bank/receiving free groceries	<input type="checkbox"/>	Mental health counseling or therapy
<input type="checkbox"/>	Help finding low income housing	<input type="checkbox"/>	Naturopathy/herbal medicine/etc.
<input type="checkbox"/>	Help managing drug or alcohol use (harm reduction)	<input type="checkbox"/>	Nutritional counseling
<input type="checkbox"/>	Help quitting drug or alcohol use	<input type="checkbox"/>	One-to-one peer emotional support
<input type="checkbox"/>	Help paying for groceries	<input type="checkbox"/>	Peer or client advocacy (other than case manager)
<input type="checkbox"/>	Help paying for medical insurance	<input type="checkbox"/>	Prescription drug program of WA State ("APDP")
<input type="checkbox"/>	Help paying rent	<input type="checkbox"/>	Skilled nursing facility
<input type="checkbox"/>	Help paying utility bills	<input type="checkbox"/>	Spiritual or religious counseling
<input type="checkbox"/>	Home care worker (paid attendant)	<input type="checkbox"/>	Support groups
<input type="checkbox"/>	Home chore volunteer	<input type="checkbox"/>	Telephone referrals to medical/dental care
<input type="checkbox"/>	Home delivered meals	<input type="checkbox"/>	Transportation/rides
<input type="checkbox"/>	Home nursing or infusion care	<input type="checkbox"/>	Treatment adherence support (help taking HIV meds correctly)

PART 5:
ARE THERE ANY OTHER COMMENTS
THAT YOU WOULD LIKE TO SHARE WITH US?

Thanks again for filling out this survey. We greatly appreciate it.
Your responses will help the Planning Council
make important funding decisions.

Please tell your friends about this survey – we'd like to hear from as many
people living with HIV/AIDS as possible.

Fold your survey and tape it closed,
and drop it in the mail by January 31, 2001.

2001 HIV/AIDS Provider Survey

The HIV/AIDS Planning Council wants to find out what the care service needs are for people living with HIV/AIDS in King County. This information will influence funding decisions that directly affect your clients.

Please take a few minutes to fill out this survey.
Your input does matter!

**ALL RESPONSES ARE STRICTLY ANONYMOUS.
PLEASE DO NOT SIGN YOUR NAME
ANYWHERE ON THE SURVEY FORM.**

Please return this survey by December 22, 2000

*HIV/AIDS Planning Council
(206) 296-4527
TTY: (206) 205-5553*

PART 1: TELL US ABOUT THE CLIENTS THAT YOU SERVE

What type of service do you *primarily* provide to your HIV/AIDS clients? (Check one)

<input type="checkbox"/>	Western medical care (MD/nurse)	<input type="checkbox"/>	Support services (food bank, transportation, volunteer home chore, etc.)
<input type="checkbox"/>	Alternative, non-Western therapies	<input type="checkbox"/>	Dental care
<input type="checkbox"/>	Case management	<input type="checkbox"/>	Substance use treatment/counseling
<input type="checkbox"/>	Housing assistance and/or services	<input type="checkbox"/>	Skilled nursing/hospice care
<input type="checkbox"/>	Mental health therapy/counseling	<input type="checkbox"/>	Adult day health program
<input type="checkbox"/>	Emotional support programs	<input type="checkbox"/>	Other: _____

What is the total number of clients with HIV/AIDS on your active caseload?
(You can estimate if you're not sure about the actual number.)

Of your **total HIV+ caseload**, what number (i.e., how many - **NOT** what percentage) fall into each of the following demographic categories? (Again, you can estimate if you're not sure.)

SEX

<input type="checkbox"/>	Male	<input type="checkbox"/>	Transgendered (M-to-F)
<input type="checkbox"/>	Female	<input type="checkbox"/>	Transgendered (F-to-M)

AGE

<input type="checkbox"/>	Under 13 years of age	<input type="checkbox"/>	25 – 29
<input type="checkbox"/>	13 – 19	<input type="checkbox"/>	30 – 39
<input type="checkbox"/>	20 – 24	<input type="checkbox"/>	40 years old and over

RESIDENCE (NOTE: Report homeless clients under the area in which you serve them)

<input type="checkbox"/>	Seattle	<input type="checkbox"/>	South King County
<input type="checkbox"/>	East King County	<input type="checkbox"/>	Outside King County

PART 4: WHAT SERVICES HELP YOUR CLIENTS GET OR KEEP MEDICAL CARE?

A lot more attention is being paid these days to helping people with HIV or AIDS get and keep the medical care they need.

Of the services listed below, which do you think are the most important in helping your clients get medical care or keep the medical care they are currently using?

**You may check up to SEVEN (7) of the services listed below.
(Please don't check more than seven).**

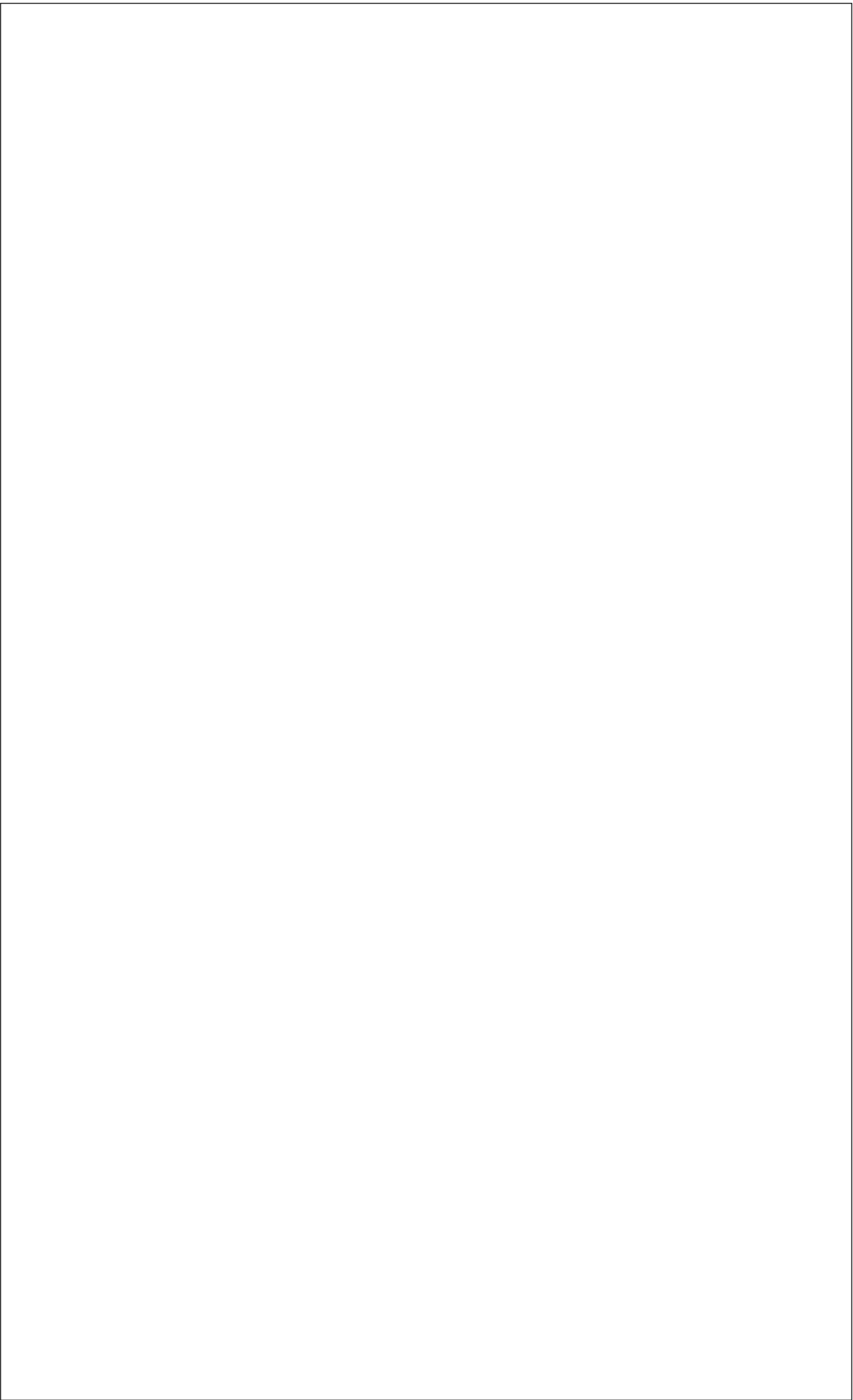
	Acupuncture or Chinese medicine		Hospice care
	Adult day health program		Information/help with safer sex or safer drug use
	Benefits counselor (other than case mgr.)		Interpreter services
	Case management		Legal assistance
	Child care		Massage therapy
	Dental care		Medical info about HIV, treatments, etc.
	Food bank/receiving free groceries		Mental health counseling or therapy
	Help finding low income housing		Naturopathy/herbal medicine/etc.
	Help managing drug or alcohol use (harm reduction)		Nutritional counseling
	Help quitting drug or alcohol use		One-to-one peer emotional support
	Help paying for groceries		Peer or client advocacy (other than case manager)
	Help paying for medical insurance		Prescription drug program of WA State
	Help paying rent		Skilled nursing facility
	Help paying utility bills		Spiritual or religious counseling
	Home care worker (paid attendant)		Support groups
	Home chore volunteer		Telephone referrals to medical/dental care
	Home delivered meals		Transportation/rides
	Home nursing or infusion care		Treatment adherence support (help taking HIV meds correctly)

PART 2: WHAT SERVICES ARE MOST IMPORTANT FOR YOUR CLIENTS?

Here is a list of services available to persons living with HIV/AIDS in King County. In thinking about the entire HIV+ client population on your active caseload, which of these services do you consider to be most important for them?

**You may check up to SEVEN (7) of the services listed below.
Please do not check more than seven services.**

	Acupuncture or Chinese medicine		Information/help with safer sex or safer drug use
	Adult day health program		Interpreter services
	Benefits counselor (other than case mgr.)		Legal assistance
	Case management		Massage therapy
	Child care		Medical care (doctor, nurse, etc.)
	Dental care		Medical info about HIV, treatments, etc.
	Food bank/receiving free groceries		Mental health counseling or therapy
	Help finding low income housing		Naturopathy/herbal medicine/etc.
	Help managing drug or alcohol use (harm reduction)		Nutritional counseling
	Help quitting drug or alcohol use		One-to-one peer emotional support
	Help paying for groceries		Peer or client advocacy (other than case manager)
	Help paying for medical insurance		Prescription drug program of WA State
	Help paying rent		Skilled nursing facility
	Help paying utility bills		Spiritual or religious counseling
	Home care worker (paid attendant)		Support groups
	Home chore volunteer		Telephone referrals to medical/dental care
	Home delivered meals		Transportation/rides
	Home nursing or infusion care		Treatment adherence support (help taking HIV meds correctly)
	Hospice care		Other: _____



PART 3: WHAT SERVICES DO YOUR CLIENTS NEED, BUT CAN'T GET?

Now we'd like you to identify the services which a ***substantial number*** of your HIV+ clients need, but are having trouble accessing.

You may check as many boxes as you wish.

<input type="checkbox"/>	Acupuncture or Chinese medicine	<input type="checkbox"/>	Information/help with safer sex or safer drug use
<input type="checkbox"/>	Adult day health program	<input type="checkbox"/>	Interpreter services
<input type="checkbox"/>	Benefits counselor (other than case mgr.)	<input type="checkbox"/>	Legal assistance
<input type="checkbox"/>	Case management	<input type="checkbox"/>	Massage therapy
<input type="checkbox"/>	Child care	<input type="checkbox"/>	Medical care (doctor, nurse, etc.)
<input type="checkbox"/>	Dental care	<input type="checkbox"/>	Medical info about HIV, treatments, etc.
<input type="checkbox"/>	Food bank/receiving free groceries	<input type="checkbox"/>	Mental health counseling or therapy
<input type="checkbox"/>	Help finding low income housing	<input type="checkbox"/>	Naturopathy/herbal medicine/etc.
<input type="checkbox"/>	Help managing drug or alcohol use (harm reduction)	<input type="checkbox"/>	Nutritional counseling
<input type="checkbox"/>	Help quitting drug or alcohol use	<input type="checkbox"/>	One-to-one peer emotional support
<input type="checkbox"/>	Help paying for groceries	<input type="checkbox"/>	Peer or client advocacy (other than case manager)
<input type="checkbox"/>	Help paying for medical insurance	<input type="checkbox"/>	Prescription drug program of WA State
<input type="checkbox"/>	Help paying rent	<input type="checkbox"/>	Skilled nursing facility
<input type="checkbox"/>	Help paying utility bills	<input type="checkbox"/>	Spiritual or religious counseling
<input type="checkbox"/>	Home care worker (paid attendant)	<input type="checkbox"/>	Support groups
<input type="checkbox"/>	Home chore volunteer	<input type="checkbox"/>	Telephone referrals to medical/dental care
<input type="checkbox"/>	Home delivered meals	<input type="checkbox"/>	Transportation/rides
<input type="checkbox"/>	Home nursing or infusion care	<input type="checkbox"/>	Treatment adherence support (help taking HIV meds correctly)
<input type="checkbox"/>	Hospice care	<input type="checkbox"/>	Other: _____

Of your total caseload, what number fall into each of the following demographic categories?

RACE OR ETHNICITY

	African American/Black		Caucasian/White
	Alaska Native		Latino/Latina
	American Indian/Native American		Other
	Asian/Pacific Islander		

PRIMARY LANGUAGE

	English		Other: _____
	Spanish		Other: _____

ANNUAL HOUSEHOLD INCOME (Based on Federal Poverty Level (FPL) Guidelines)

	Under 100% of FPL (under \$8,500)		Between 200% - 300% (\$17,001-\$25,000)
	Between 100% - 200% (\$8,501-\$17,000)		Above 300% (Over \$25,000)

TRANSMISSION CATEGORY

	Gay/bisexual male		Recipient of transfusion or blood products
	Injection drug user		Perinatal (mother with HIV)
	Gay/bi male <u>and</u> injection drug user		Other: _____
	Heterosexual transmission		

OTHER DEMOGRAPHIC INDICATORS

How many of your clients have a history of <u>chemical dependency</u> ?	
How many of your clients have been diagnosed with a <u>mental illness</u> ?	
How many of your clients have been <u>homeless</u> in the past twelve months?	
How many of your clients have been <u>in jail or prison</u> in the past twelve months?	

PART 5:
ARE THERE ANY OTHER COMMENTS
THAT YOU WOULD LIKE TO SHARE WITH US?

Thank you for filling out this survey. We greatly appreciate it. Your responses will help the Planning Council make important funding decisions.

**Please fold and tape your survey closed
and drop it in the mail by December 22, 2000.**

2001 HIV/AIDS CARE SERVICES NEEDS ASSESSMENT FOCUS GROUP SCRIPT

1) Introduction of facilitator/host/note taker

- thank hosting agency for co-sponsorship
- remind participants to help themselves to food/beverages
- group is scheduled to take 1.5 hours, may take less depending on response
- participants who stay the full 1.5 hours will receive \$20 at the end of the meeting
- Reimbursement for transportation and child care, if needed, is available
- Remind participants that they cannot participate in more than one focus group (i.e., since they are at this one, they cannot attend another one)

2) Overview of care services needs assessment process

- needs assessment mandated by receipt of federal Ryan White CARE Act \$ to ensure that the \$ are used to support appropriate services
- Planning Council works with Public Health – Seattle & King County and community agencies to assess these needs
- needs assessment includes interviews with and surveys of services providers, consumer surveys and focus groups
- the information we gather will be used to make funding decisions for HIV/AIDS services in upcoming years
- it will help the Planning Council examine if the HIV/AIDS care system is working (for consumers overall and for specific sub-populations of consumers)

3) Statement of confidentiality

- statements at this focus group will be treated as strictly confidential
- no names will be used in reporting the information collected from the group
- group will be taped for more effective transcription of statements - names will not be attached to any quotes
- assignment of individual names (use first names or initials only on name tags - can be real or made-up)

4) Ground rules

- speak in “I” sentences
- one person speaks at a time
- respect the opinions of everyone in the group
- talk about what’s working as well as what needs improvement
- can talk about services and specific agencies but not about specific people
- what is said in the room stays in the room
- everyone participates
- Any other ground rules the group wants to identify?

5) Introductions/icebreaker

- Ask each participant to introduce themselves (first name only)
- Icebreaker: tell us something good that happened to you this week

6) First, let's talk about when you first learned that you were HIV+.

- Where did you learn you were HIV positive? (in what city, in what type of setting – doctor's office, hospital, community clinic, etc.)
- What was the experience like?
- What worked for you? What could have been done differently?
- When you learned you were positive, were you informed about how to get medical care and other services?

7) Next we'd like to talk about your experiences in getting medical care for your HIV, at the time you first discovered you had HIV.

- How long after you discovered you were positive did it take for you to get medical care for your HIV?
- Tell us about your experience in accessing care for HIV. Was it difficult or easy to find a doctor?
- What worked for you about your care? What didn't?
- Were there any barriers you experienced in getting care? If so, what were they?

8) Now we'd like to ask you if you are currently getting medical care related to having HIV.

- If you are currently receiving care, where are you getting it?
- Are you satisfied with the kind of medical care you are getting? Why or why not?
- If you're not receiving care, why not?
- Do you know of any friends or acquaintances [from the specific population] who have HIV and are not getting medical care? Have they told you any reasons about why they are not getting care?

9) When you think about the kind of services that you need to stay in control of your health and your life, what kinds of services come to mind?

- These can be both medical services and other services that you're using, like case management.

10) As I mentioned earlier, we conducted a survey of many different kinds of people who are living with HIV in King County. I'd like to get your opinion on some of the information that (specific sub-population) gave us on the survey.

- (Facilitator refers to survey data about priorities, gaps and access barriers, highlighting major response differences.)
- Why do you think these differences exist?
- Do these answers represent the way you feel?

11) Is there anything else you'd like to share with us?

12) Thanks and closing

- Have participants who are leaving sign for reimbursements

**2001 HIV/AIDS CARE SERVICES NEEDS ASSESSMENT
PROVIDER INTERVIEW**

POPULATION:_____

NAME _____

TITLE/POSITION _____

AGENCY _____

PHONE _____

Approximately how many PLWH in the target population have you worked with in the past year?

CLIENT DEMOGRAPHICS: How would you characterize your client population in each of the following areas? Have you observed any trends or changes in the make-up of your caseload in these areas in the past year?

1) Sex:

2) Age:

3) Race/ethnicity:

4) Place of residence (Seattle/South KC/East KC/Homeless):

5) Primary language:

6) Annual income:

7) Transmission category:

8) Immigration status:

9) History of incarceration:

HEALTH INDICATORS: Tell me about how your clients are doing in regards to each of the following health indicators. Are there any changes or trends you've observed in these areas in the past year?

1) HIV health status:

2) Access to/compliance with HIV medications:

3) Mental health status:

4) Substance use status:

REFER TO THE SERVICE COMPARISON LIST: As you know, we conducted surveys of providers and consumers earlier this year. We'd like to ask your opinion on some of the results and how they relate to the specific population you serve (NOT just your clients, but the entire sub-population.)

1. In general, have you seen any trends or change in the kinds of services your clients are using or seeking in the past year versus several years ago?

2. Let's start with how consumers prioritized the services available to them, in other words, what services they thought were most important. Here's a comparison between your population and other consumer populations. Do you have any insights on the highlighted results?

Are there any other results on the list that stand out for you?

3. Now let's look at the services that consumers said help them access medical care, in other words, what services they thought were most important to help them get or keep medical care. Here's a comparison between your population and other consumer populations. Do you have any insights on the highlighted results?

Are there any other results on the list that stand out for you?

4. And finally, here's a look at which services consumer identified as gaps, in other words, what services they need but don't think they can get. Here's a comparison between your population and other consumer populations. Do you have any insights on the highlighted results?

Are there any other results on the list that stand out for you?

5. Are there any specific barriers that impede your clients' ability to access services? If so, what are they?

How would you suggest we begin to work to overcome the barriers which make it difficult or prevent your clients from receiving services they need?

Any further comments or suggestions?

2001 HIV/AIDS CARE SERVICES NEEDS ASSESSMENT
Collapsing Services on the Consumer and Provider Surveys
Into Ryan White Funding Categories

Ryan White funding category	Includes these services on the survey...
Adult day health	Adult day health program
Alternative, non-Western therapies	Acupuncture or Chinese medicine Naturopathy, herbal medicine, etc.
Ambulatory/outpatient medical care	Medical care (doctor, nurse, etc.)
Case management	Case management
Child care	Child care
Client advocacy	Benefits counselor (other than case manager) Medical information about HIV/AIDS, tx., etc. Interpreter services Peer or client advocacy (other than case mgr.)
Counseling (emotional support)	Support groups One-to-one peer emotional support Spiritual/religious counseling
Dental care	Dental care
Direct emergency financial assistance	Help paying utility bills Help paying for groceries
Drug prescription program	Prescription drug program of WA State
Food/meals	Home delivered meals Food bank/receiving free groceries
Health education/risk reduction	Information/help with safer sex or risk reduction
Home health care	Home care worker (paid attendant) Home nursing or infusion care Skilled nursing facility
Housing assistance/housing related services	Help finding low income housing Help paying rent
Insurance programs	Help paying for medical insurance
Legal assistance	Legal assistance
Mental health therapy/counseling	Mental health counseling or therapy
Referral	Telephone referrals to medical or dental care
Substance use treatment/counseling	Help managing drug/alcohol use (harm reduction) Help quitting drug/alcohol use
Transportation	Transportation/rides
Treatment adherence support	Treatment adherence support (help taking meds)

Volunteer home chore	Home chore volunteer
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